

ALZHEIMER'S DISEASE

HEARING
BEFORE THE
SUBCOMMITTEE ON AGING
OF THE
COMMITTEE ON
LABOR AND HUMAN RESOURCES
UNITED STATES SENATE
ONE HUNDREDTH CONGRESS
FIRST SESSION

ON

EXAMINING THE PROGRESS THAT HAS BEEN MADE IN COMBATING
ALZHEIMER'S DISEASE AND TO DISCUSS THE FURTHER ADVANCES
NEEDED IN HELPING TO DEFEAT THIS DISORDER

AUGUST 19, 1987, CLEVELAND HEIGHTS, OH



Printed for the use of the Committee on Labor and Human Resources

U.S. GOVERNMENT PRINTING OFFICE

WASHINGTON : 1987

78-775

For sale by the Superintendent of Documents, Congressional Sales Office
U.S. Government Printing Office, Washington, DC 20402

COMMITTEE ON LABOR AND HUMAN RESOURCES

EDWARD M. KENNEDY, Massachusetts, *Chairman*

CLAIBORNE PELL, Rhode Island
HOWARD M. METZENBAUM, Ohio
SPARK M. MATSUNAGA, Hawaii
CHRISTOPHER J. DODD, Connecticut
PAUL SIMON, Illinois
TOM HARKIN, Iowa
BROCK ADAMS, Washington
BARBARA A. MIKULSKI, Maryland

ORRIN G. HATCH, Utah
ROBERT T. STAFFORD, Vermont
DAN QUAYLE, Indiana
STROM THURMOND, South Carolina
LOWELL P. WEICKER, Jr., Connecticut
THAD COCHRAN, Mississippi
GORDON J. HUMPHREY, New Hampshire

THOMAS M. ROLLINS, *Staff Director and Chief Counsel*

HAYDEN G. BRYAN, *Minority Staff Director*

SUBCOMMITTEE ON AGING

SPARK M. MATSUNAGA, Hawaii, *Chairman*

CLAIBORNE PELL, Rhode Island
HOWARD M. METZENBAUM, Ohio
CHRISTOPHER J. DODD, Connecticut
EDWARD M. KENNEDY, Massachusetts
(Ex officio)

THAD COCHRAN, Mississippi
STROM THURMOND, South Carolina
LOWELL P. WEICKER, Jr., Connecticut
ORRIN G. HATCH, Utah
(Ex officio)

LOIS FU, *Staff Director*

JACKIE KNOX, *Minority Staff Director*

CONTENTS

STATEMENTS

AUGUST 19, 1987, CLEVELAND HEIGHTS, OH

	Page
Bonder, Evelyn, former caregiver and legislative assistant to Senator Howard M. Metzenbaum, Washington, DC; Edward R. Truschke, president, National Alzheimer's Disease and Related Disorders Association, Chicago, IL; and Stanley J. Brody, MSW, JD, professor, Physical Medicine and Rehabilitation, Hospital of the University of Pennsylvania	10
Brody, Drs. Stanley J. and Elaine M., prepared statement	19
Cook-Deegan, Robert, MD, senior analyst and project director, Office of Technology Assessment, U.S. Congress; Zaven Khachaturian, Ph.D., vice-president of research, Medical and Health Care Division, University of Pittsburgh; Peter Whitehouse, MD, Ph.D., director, Alzheimer's Center, University Hospital, associate professor, Department of Neurology, Case Western Reserve University, Cleveland, OH	28
Prepared statements of:	
Dr. Cook-Deegan	32
Dr. Khachaturian	39
Dr. Whitehouse	57
Peters, Tom, Lucille Thompson, Bobby Blankenship, and Dianne Godesa, caregivers	3

ADDITIONAL MATERIAL

Articles, publications, etc.:	
OTA proposal—Methods of locating and arranging health and long-term care services for persons with Dementia	66

ALZHEIMER'S DISEASE

WEDNESDAY, AUGUST 19, 1987

U.S. SENATE,
SUBCOMMITTEE ON AGING
OF THE COMMITTEE ON LABOR AND HUMAN RESOURCES,
Cleveland Heights, OH.

The subcommittee met, pursuant to notice, at 10 a.m., at the Judson Auditorium, Cleveland Heights, OH, Senator Howard M. Metzenbaum presiding.

OPENING STATEMENT OF SENATOR METZENBAUM

Senator METZENBAUM. I'm Senator Howard Metzenbaum, chairman of this field hearing on Alzheimer's Disease for the Aging Subcommittee.

It's a rather incongruous situation for me this week. A few days ago I was in Cleveland in connection with AIDS babies, and today I am here in connection with Alzheimer's patients. That covers the whole life spectrum, from the very tiniest to some of our senior citizens.

I was here—as a matter of fact, in this very room almost three years ago. At that time I said my aim was to foster a better understanding of Alzheimer's Disease and the toll it exacts on so many lives. In addition, we tried to expose some of the cracks in our health-care system in this regard and talked about possible means of sealing those cracks.

I felt that we were successful on those counts, and that the Subcommittee's hearing in November of 1984 gave us a foundation on which to build. Therefore, I thought it would be helpful to meet here again today in order to discuss the many things that have happened since and the work that lies ahead of us, and there is much work that lies ahead of us.

I will be frank—we will hear testimony today that is hauntingly similar to what we heard in 1984, particularly for the caregivers struggling to cope with this awful menace. The burdens, physical and emotional, for the families and loved ones of the victims remain tremendous.

I was just talking with one of those who has a beloved wife who has been with him for 15 years of constant care at home, and we will hear from him today. But I believe we will also be presented with testimony of hope, news of exciting research underway in an effort to unlock the mystery of this cruel killer.

Three years ago I reported that an amendment I had offered resulted in the creation of five specialized Alzheimer's research centers. Today, the number of Federally funded centers has grown to

10. The number of scientists and researchers concentrating on Alzheimer's continues to grow. We haven't solved the problem, we have much to do, but we will, we will solve it. Today we will also hear of some unique, innovative approaches to help caregivers live more livable lives.

From a legislative standpoint, I can tell you that we're making headway. As a matter of fact, I can tell you that when I offer an amendment or proposal in connection with Alzheimer's, it's amazing—they come out of the woodwork, so many who say, "My father has Alzheimer's, my sister has Alzheimer's," and it's not difficult for me to get legislation through having to do with Alzheimer's.

The Omnibus Health Measure, which was passed last year, included my Alzheimer's Bill and provided \$5 million for medical research, \$8 million in health services research, a million for educational activities, \$300,000 for an information clearing house, and created a National Alzheimer's Disease Advisory Panel, a considerable grouping of provisions to help alleviate some of the problems.

This year my amendment to the Older Americans Act Reauthorization provides \$25 million for caregiver support services, including functional assessments, prenursing-home admission counseling, adult day care, respite care, and home health aides.

If you recite one of those words, one of those phrases, it doesn't sound like much—respite care, adult day care, home health aides that is, it doesn't seem like much unless you happen to be one of the families involved with an Alzheimer's patient, then it may mean the difference between a livable life and an almost intolerable situation.

We're chipping away at the problems, and I sincerely hope that the assistance we're starting to provide will become available to caregivers as soon as possible.

I don't need today to recount the staggering statistics that are involved here, the millions of victims, the thousands of deaths, the billions of dollars, the shattered lives. Alzheimer's Disease, like AIDS, seemed to come out of nowhere, with such fury that explanations and analysis of the numbers seemed, somehow, unnecessary.

Whoever heard of Alzheimer's Disease 20 years ago? Then suddenly it came, and its persuasive impact upon our society became a reality.

Alzheimer's Disease has intruded into our existence, leaving few untouched in some way.

Today we have a distinguished panel of important witnesses who can help us with this reassessment. I am anxious to hear their testimony and, without further delay, let's turn to our first panel of witnesses, those most affected, the caregivers. Tom Peters, Lucille Thompson, Bobby Blankenship and Dianne Godesa, will you please come to the table.

I'm going to ask each of the witnesses to try to limit their comments to five minutes, at the outside 10 minutes, so we can cover all of our witnesses today.

Tom Peters is our first witness, and his testimony is particularly significant to me. We were in business in this community for some years; Tom Peters was the first employee that we had in our company. And so we go back a long ways, not alone in an employer/employee relationship, but in a personal relationship. I'm happy

that Tom Peters is here today; I'm sad that Tom Peters has a situation that warrants his being here today.

I knew well his beloved wife Ann, and Tom, we want to hear from you about your situation.

STATEMENTS OF TOM PETERS, LUCILLE THOMPSON, BOBBY BLANKENSHIP, AND DIANNE GODESA, CAREGIVERS

Mr. PETERS. Thank you, Howard. Please forgive my voice, I'm just getting over a cold——

Senator METZENBAUM. Bring the mike a little closer, please.

Mr. PETERS [continuing]. I wanted to be sure to be here today to talk with everyone here and to tell you our situation.

It's nice to see you again, and I'm most grateful for everything you have been doing for the Alzheimer people. It's most important.

Howard, as you know, Ann is now 72 years of age. Fifteen years ago she began having problems with her memory, and all sorts of aggravating situations. In 1974, it was finally determined that Ann had Alzheimer's Disease.

In the 15 years that I've been taking care of Ann, the eight years Ann is bed-bound, cannot talk, cannot move. If a fly were to get on her nose, she couldn't touch it. She needs horribly, horribly lots of care. I have a distinct problem because my love for her prevents me from putting her into a nursing home. I've just celebrated my 50th wedding anniversary, and it wasn't a good anniversary because she wasn't able to enjoy it.

Over the years, it has averaged anywhere from \$18,000 to \$20,000 a year for me to pay for the care and the love that we can give to Ann. It takes a nurse during the day, it takes doctors, it takes physical therapists. I have a full time job. I had retired, as you know; I had to go back to work because of the cost of taking care of Ann. Before I can buy a stick of bubble gum a week, I must put out \$300 to \$400 a week.

I have gone to every agency, county and otherwise, in the early days of this disease, trying to get assistance. The most I could get would be help for two hours, four hours at the most, and if I could afford it, I'd have to pay for it.

There is no agency, that I know of, in today's field except for that which is given to us by the Alzheimer's groups that we have been able to form and work with. The doctors tell me that there is no hope for her, and she just lies there.

The caregiver is the problem that I speak of today. The caregiver needs assistance. I have a full Blue Cross Plan with the city of Cleveland, but it does not cover my wife. They consider it to be custodial care and, consequently, won't help, won't pay for anything. The only help I get and the only aid is from Medicare, the 80 percent that they pay, and that isn't sufficient.

There is a need to work with the caregivers to give them the hope that there will be a solution to this, and I am sure it will come. Unfortunately, for people like my wife, there is no hope. It is too far gone. I look forward, hopefully, to the day when this can end. It is a terrible disease, and the caregiver is the biggest sufferer of all.

My wife is in a vacuum of her own, and we give her loving care daily, but the caregiver is beginning to break down. I'd like to retire, I'd like to rest, and I can't; I must continue to work. And I ask your aid and the aid of anyone else that can help to do something in that regard.

Senator METZENBAUM. Thank you very much, Tom.

I think I'm going to hear from all the witnesses before I ask any questions. Our next witness is Lucille Thompson.

Ms. THOMPSON. When I first noticed that my mother had Alzheimer's, she was cooking breakfast and she forgot that she was cooking, and she burned up the breakfast.

She started hiding food, her clothes, the Social Security check, and the door and car keys.

Then she started walking out of the house at night with no clothes on.

I'm kind of nervous. I'm sorry, I'm kind of nervous.

Senator METZENBAUM. Please relax. Don't be nervous.

Ms. THOMPSON. She would go outside with no clothes on, in the snow. She would fight and curse. I would dress her; she would take her clothes off saying they were someone else's clothes.

Then on Sundays when we were getting ready to go to church, I'd have a time getting her ready for church. After I had gotten her ready for church and I would go in to get myself dressed, by the time I came out of the tub, she was undressed. Then I'd have to go back and dress her, then come back and try to dress myself. It was just terrible.

She loves to play in water in the bathroom and tear up tissue paper. She puts paper all over the hall, bathroom, and her bedroom floor.

She's always said to us, before her mind got bad, to never put her in a nursing home, and I promised. My father asked me the same thing, not to put her in a home. I told him that I would try to keep her as long as I could. I did send her to day care here for a year, but she didn't have that much money and her money ran out, so I had to stop sending her. Anyone that does anything for you, they want you to pay them. I don't have the money to pay them, so I just have to put up with it myself.

Senator METZENBAUM. Thank you very much, Ms. Thompson.

Bobby Blankenship, we will be happy to hear from you, young man.

Mr. BLANKENSHIP. Senator Metzenbaum, my name is Bob Blankenship.

My mother was diagnosed in 1983 as having Alzheimer's. She was 48 years old at the time. There is no help for her, no way. We have been everywhere to find something, and it's just me and my dad to care for her. My father transferred to the night shift and I delayed seeking full-time employment so we could care for my mom.

She is in West Virginia right now in a nursing home. The nursing home costs \$65 to \$70 a day. We couldn't take care of her any more. I was trying to get work in other places, and my dad works full time for Ford Motor Company. My dad's sister took the responsibility of helping us out.

She has very bad bedsores now. She's always getting pneumonia. She will not eat; she can not eat. She's just like a baby, an infant in bed; and she's only 52. There's no hope for someone that young. There has to be something to cure this disease and to help caregivers.

Now she is in the nursing home, and it's draining us. My father who has worked hard his entire life so they could retire is now \$30,000 in debt, and the bills keep coming. I just don't know what else to say.

Senator METZENBAUM. Thank you, Bobby. I'll have some questions.

Mr. BLANKENSHIP. Thank you.

Senator METZENBAUM. Our last witness in this panel is Dianne Godesa.

Ms. GODESA. It's an honor to speak to you today, Senator Metzenbaum.

I am married and the mother of four children. I am the caregiver for an Alzheimer victim, my mother.

In 1983 when she was 65 years old, she was diagnosed as having the disease. Getting my mother to the doctor and obtaining her cooperation for the tests that were required was one of the most trying times in my life. She was always a tough-minded, take-charge individual, and taking my advice was not her way.

After the tests were completed and the diagnosis was made, I knew that some very serious decisions were ahead of me. It was an uphill battle. Mom lived alone, 40 miles away from me; my father is dead; I am her only daughter. It was obvious that I had to do something.

There was only milk in her refrigerator. She had no food in her pantry. Money was scattered everywhere throughout the house. Dirty clothes were hanging everywhere. The floor had papers and clothing all over it. The doors were left wide open, and the furnace was continuously running and set at over 80 degrees. A dog had ripped the screens and was jumping in and out through the holes in the door. My mother's hair had been chopped off here and there and was in disarray, and she was very dirty.

These details are not easy for me to relate this way, but I want you to understand more clearly about the difficulty with Alzheimer's Disease. Believe me, this was not the mother I once knew. She was once very attractive, meticulous and bright.

Mother was firm about not selling her home of many years. She said she was definitely not going to move. And it was my private hell to get her off the streets, for her own safety and that of an innocent victim. She had been cited three times in a 12-week period.

She would drive down a busy highway or street very, very slowly—sometimes with her trunk wide open. You see, she punched out the lock because she was always losing the trunk key and she liked to hide her money in her trunk, thus the trunk would fly open as she drove. In fact, she was clever enough to have a mechanic install an instant start on her steering column, which meant she didn't need a key to start her car.

Mom drove through red lights. She drove with doors ajar. She was often lost. A trip to my home would take her all day. When it

rained, she did not know how to turn on the wipers. She had all the knobs pulled off the radio. Again, I feared for her life and that of others.

Finally, I was able to have a doctor and a judge take her driver's license away. It was terribly frustrating and complicated, dealing with the Bureau of Motor Vehicles in Columbus. I recall calling them often, because Mom was still able to get a new driver's license, simply by saying she had lost the other one.

Then came the task of telling her we were selling her car. We had to do this because even when we removed small parts to prevent her driving the auto, she would have a mechanic come and get it started again. She was determined to keep driving.

It's painful to recall the problems this automobile gave me. Adding to the pain is the disgusting fact that she paid a sharp salesman over \$4,000 for the auto and its value was only \$1,200. She even managed to block my legal attempts to have the dealer rescind the contract. She didn't care about being taken advantage of—she just wanted her car. Her judgment was totally impaired.

I'm giving you some examples of what it is like to deal with a victim of Alzheimer's Disease. In reality, I was taking away my mother's life, her independence, her dignity. It was a complete, uncomfortable role reversal: I was the parent and she the child. It was terribly traumatic and difficult for both of us.

Mother did not want to live with me. She wanted her own home. She fought me constantly. I tried to compromise with her; I bought her a home five minutes away from me. It didn't work. I was there several times each day, and would look in on her during the evenings. I did her housework and saw that she was kept clean. I obtained Meals-on-Wheels and had a milkman deliver milk and other food items to her. She resented my interference, and her eating became uncontrollable. This lasted six months.

The neighbors complained, Mother started night wandering. After the police found her at the Berea Fairgrounds, and the local hospital became involved, I knew I, again, had to make decisions that would anger her. I had to protect my mother, and she made that next to impossible. She was combative.

Everyone said she belonged in a nursing home; I could not face that thought. She was healthy, could hold a conversation well, and she had been through so much. I felt a nursing home would really kill her spirit. I pictured her tied to a chair and to a bed; my mother would not be able to handle that. I pictured her drugged, and it saddened me.

Today, four years later, my mother—much thinner now—is still with me. She is usually quiet, and I have difficulty getting her to eat well. I dress her, bathe her, clean up her accidents, do her laundry, take her to the hairdressers, doctor and dentist. I answer her questions, the same questions, over and over. I calm her fears about the lady in the mirror.

I look back and wonder how I ever accomplished so much. I am thankful for the Southwest Adult Day-Care Center. It helps me tremendously. We are fortunate that it is close by. We need more day-care centers. If I did not have anywhere to send her, I don't know what I would do. If I had to hold a full time job, I don't know what I would do. I am also, indeed, fortunate to have a loving husband.

Now, let me tell you of another Alzheimer's situation. My mother-in-law also has Alzheimer's Disease. She is 82. She was diagnosed 12 years ago. She is now bedridden and doesn't speak. She doesn't recognize her only child, my husband.

My father-in-law is 83, and he is her caregiver at home. You wonder, "How can this be possible?" They live in Canada, Senator. With the government's help, he is able to keep his wife of over 50 years at home with him. Five days a week someone is there to help. The Victorian Order of Nurses are there two days a week to check on her health and see to his needs. Three days a week, a home-care person is there for three hours each day. She bathes her, cleans the house and does the laundry. They also have Meals-on-Wheels. The best part: my father-in-law pays nothing for this service.

We feel that if she were in a nursing home, he would not survive. He worships her. He lovingly feeds her and keeps her clean. He sits by her bed and reads to her. We think that this is why she looks so well and still manages to smile for him.

How grand it would be if other families in the United States, could be able to keep their loved ones at home where they want them, if only there were help available.

I believe that many of the tragedies that we read about in our newspapers stem from the helpless, hopeless way people are living through this difficult disease. Many are so alone and feel that no one cares. They don't even begin to know where to ask for help. They cannot cope. They become desperate, and some do terrible things.

The caregiver and victim need respect and assistance. They, too, deserve the help of our government. Let's not forget them. Thank you.

Senator METZENBAUM. Very, very telling testimony; in fact, powerful. I wish I could wave a wand and do something about it, but you know as well as I do that that's not possible, and you cannot turn the clock backwards for these poor souls whom each of you give such loving care to.

Tom, it's my understanding that you spend about 50 percent of your total income taking care of Ann; non-tax deductible; right?

Mr. PETERS. That's correct, sir.

Senator METZENBAUM. This has gone on now for 15—

Mr. PETERS. Fourteen years.

Senator METZENBAUM. Fourteen years.

Dianne, you're telling us the story of your father-in-law's situation in Canada—I mean mother-in-law's situation, and the Canadian Government providing that kind of care. I think we're moving in that direction. We aren't there yet, a long ways from it, but I think some of the pending legislation would move us in that direction. We're trying.

Lucille, you have a burden and probably a tremendous sense of inner resentment in you—and my guess is, each of you have a kind of resentment, "Why did this happen to us?"

Bobby, you tell me about your mother who was 48 years old when she came down with Alzheimer's.

If you asked 230 million Americans about Alzheimer's, maybe only 30, 40, 50 million would know something about it. Most of

them would say, "Well, only old people get that. It's an old man's disease, old woman's disease." Your mother was 48.

Lucille, how old was your mother when she came down with it.

Ms. THOMPSON. My mother, she was about 75, somewhere around there.

Senator METZENBAUM. Tom, your wife was only about what?

Mr. PETERS. Fifty-six, sir.

Senator METZENBAUM. Fifty-six. And Dianne, I think your mother was—

Ms. GODESA. Sixty-five, Senator.

Senator METZENBAUM. Sixty-five. Let me ask you a question. Any one of you can answer, all of you can answer.

Is there some one thing you would recommend that could make your life, as a caregiver, easier right now? Dianne?

Ms. GODESA. Just as an example, I live in Strongsville, and it isn't always easy for me to get my mother to the adult day-care center. I called the Strongsville Senior Jitney to see if they would drive there, because Middleburg Heights does this for their citizens, and they said no. They only go there once a month at 4 in the afternoon.

I can't understand this. I'm paying taxes there. They're driving around healthy senior citizens, but they are unwilling to drive someone with a mental problem, so that my mother could spend a day and have a nice social time with others.

Senator METZENBAUM. Somebody on my staff will call them and see if we can't help persuade them to move in that direction, and follow up.

Ms. GODESA. Thank you.

Senator METZENBAUM. Bobby, you're a young man; how old are you.

Mr. BLANKENSHIP. I'm twenty-four.

Senator METZENBAUM. And what do you do, Bobby?

Mr. BLANKENSHIP. I'm a laid-off airline worker and into the trucking outfit—I'm just about ready to get a new job.

Senator METZENBAUM. And you've now seen your mother come down with Alzheimer's, and your dad is in the hospital for nervous exhaustion?

Mr. BLANKENSHIP. Yes, sir.

Senator METZENBAUM. He had been well prior?

Mr. BLANKENSHIP. Right. He had been very well and very, very strong until about two weeks ago. He went into the hospital with an angina attack. His heart was pounding at 150 beats a minute, and he said it felt like an elephant was sitting on his chest. My aunt took him to the hospital, and he has been in the hospital for two weeks now. My aunt thinks that he was on the verge of a nervous breakdown.

Senator METZENBAUM. I asked what one thing you might recommend to make your life as a caregiver easier now. Dianne answered; does anybody else care to answer? Bobby?

Mr. BLANKENSHIP. Yes, sir. Instead of requiring people to be age 62 or 65 and older to get medical help through Medicare or Medicaid, it should be for anybody who has this disease. People need help in providing the care these people need and deserve. I've heard of people at the age of 18 getting Alzheimer's Disease.

Senator METZENBAUM. Is that right?

Mr. BLANKENSHIP. Yes, sir.

Senator METZENBAUM. I've never heard that.

Mr. BLANKENSHIP. I heard one instance of it. It's not a very common thing but it did happen.

Senator METZENBAUM. Lucille, do you have anything that you would say that would help you specially?

Ms. THOMPSON. I think it would help me if my sister or someone would take my mother for a week, once every month or so. If my sister would keep her at her house, that would help me a lot.

Senator METZENBAUM. She's totally indifferent, and isn't willing to help at all.

Ms. THOMPSON. No, she won't help at all. Said she won't tie herself down.

Senator METZENBAUM. Where does she live?

Ms. THOMPSON. She lives in Indian Hills, and she works at Highland Hospital. Of course, I was working, too, but I had to quit my job. I was working at Judson Manor, and I had to quit my job to take care of my mother.

Senator METZENBAUM. Your husband must be a wonderful man——

Ms. THOMPSON. Yes, he is.

Senator METZENBAUM [continuing]. To accommodate the situation.

Ms. THOMPSON. Yes, he is. He's sitting back there now, my husband. He is a wonderful man.

Senator METZENBAUM. Thank you, sir.

Do any of you have anything else you'd like to add? Tom?

Mr. PETERS. In my opinion, what we need, as caregivers, is the help of people like Blue Cross and the others who can supply this aid at a reduced rate or free, as they do for some of the other diseases.

To me, the love and care that my wife Ann gets, that I give her and that my family gives her, is fine. The problem I have is that at my age I must still continue to work a full schedule in order to take care of these problems financially. The financial aid that can be given to Alzheimer's caregivers would be of great, great help.

I think, that as Dianne said, in Canada it's all taken care of; why can't it be done here? Billions and billions of dollars for nukes and other things, why not some of it for people like Alzheimer's.

Senator METZENBAUM. You don't have to convince me; I'm convinced.

Thank you all very much. Your testimony has been very meaningful, very important. I must tell you that there really is nothing that helps a Senator or Congress person more than the actual testimony of people who are involved, people who are living the experience about which we are attempting to legislate. You've been very helpful. Thank you very much.

Mr. PETERS. Thank you, Senator.

Senator METZENBAUM. Our next panel consists of three people. In a departure from normal procedure, one of the witnesses will be a member of my staff. It isn't, normally, a procedure. But this person testified so effectively on this problem as one who had lost a be-

loved husband to Alzheimer's at the last hearing, an old friend, and I urged her to come to Washington to be a member of my staff.

I don't think that anybody's staff, in the 535 members of Congress, has an individual who is more devoted or dedicated or concerned about Alzheimer's patients than Evelyn Bonder. So we are changing the usual procedures, and asking her for her comments today. I know that she was formerly active in the organization that deals with Alzheimer's patients.

Our second witness, Mr. Truschke, is President of the National Alzheimer's Disease and Related Disorders Association of Chicago. Our third witness is Stanley Brody, JD, Doctor of Jurisprudence, Professor in Physical Medicine and Rehabilitation, at the Hospital of the University of Pennsylvania.

I think you heard my comments with respect to the earlier witnesses. We would like to have you try to hold your comments to five minutes, and certainly not in excess of 10 minutes.

Evelyn, we will be glad to hear from you first.

STATEMENTS OF EVELYN BONDER, FORMER CAREGIVER AND LEGISLATIVE ASSISTANT TO SENATOR HOWARD M. METZENBAUM, WASHINGTON, DC; EDWARD R. TRUSCHKE, PRESIDENT, NATIONAL ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, CHICAGO, IL; AND STANLEY J. BRODY, MSW, JD, PROFESSOR, PHYSICAL MEDICINE AND REHABILITATION, HOSPITAL OF THE UNIVERSITY OF PENNSYLVANIA

Ms. BONDER. Senator Metzenbaum, I don't have to introduce myself.

Senator METZENBAUM. You might say a word, though, Evelyn, about your involvement with—is it ADRDA—because you were very active here in the Cleveland community, and I think you still maintain a relationship with that group.

Ms. BONDER. Oh, yes.

Senator METZENBAUM. So why don't you say a word about that, just a word about your own experience.

Ms. BONDER. I certainly will.

First, I must say that I'm delighted to be here in Cleveland today. These are my lifelong friends—I think many of them are here. My dear family is here, and the remarkable group of people, ADRDA. I don't know how I would have survived without them.

I know it's unusual for a member of your staff to testify before you, but I'm not so much testifying for you as for the people here whom I left some two and a half years ago.

It was almost three years ago, in November of 1984, that you chaired the hearing for the Subcommittee on Aging here at Judson Park. My husband had died of Alzheimer's Disease in 1983, and I was a witness then to the tragedy of the disease for the victim and for the family and testified, as you have heard these other witnesses testify, to the despair and the sorrow over the living death of someone you love.

The emotional, physical and financial burdens were devastating, and are for the witnesses you heard today. And yet, I testified I was more fortunate than most because I had the support of family, of friends and of the Cleveland Alzheimer Chapter.

And I was to become even more fortunate because, following that hearing, you made me an offer that I couldn't refuse: the opportunity to help you create legislation, on a national level, that could help Alzheimer victims and their families. It was a unique and exciting opportunity.

I admit to some hesitation about leaving all the good people here but, as always, my wonderfully wise children were encouraging and supportive. So I left my family, sold the house we had lived in for 30 years, and I flew the nest. My destination was Washington, to become an employee of the U.S. Senate. I faced a new life, a new challenge, a new, exciting, hope-filled opportunity.

The Hill, where the Congress works, is unlike any other experience in this world. The pace is fast, frenzied, hectic, with constant deadlines, but progress is much more methodical.

It requires an enormous amount of work and patience to move any legislation forward; discussion with those who are involved, as those today; consultation with the experts, as those here today; advocacy organizations, hearings, briefings, position papers, policy papers, bill drafting, support building, committee markups, committee reports—I see you smiling. I know you are most familiar with all of this.

Senator METZENBAUM. That's what I have such a great staff for—they do all that work.

Ms. BONDER. The authorizations and the appropriations. I was initiated into all of it, and more, marveling all the time at the miracle of legislation, authorized, passed, becoming public law on a national level for Alzheimer's Disease. And I'm proud that the Senator I work for has taken a leading role in developing Alzheimer's legislation, and grateful to have had an opportunity to help.

Progress has been made. There are research centers. There is increased funding for research, though still far from enough. P.L. 99-660 is in place. It is supported by ADRDA and now awaiting funding. We're working now to provide the \$25 million for family caregiving services that are so desperately needed, including the respite care and home health aides, and adult day care, and the counseling. Your National Alzheimer's Disease Advisory Panel is in place.

At the last hearing, you may remember, I testified that when my husband was diagnosed just eight years ago, we had never heard of Alzheimer's Disease, and now it's a household word. Not a day goes by without reference to it somewhere in this country—many places in this country.

Last week more than a dozen news articles were brought to my attention, some on THA, some on other research, some on caregiver stress, some on the financial burden.

Calls have been coming in from all over the country inquiring about the new drug, the clinical trials, the research centers you helped to establish.

Last week I received a call from the New York City Commissioner on Aging about Mayor Koch's Fifth Annual Conference on Alzheimer's Disease. Last week a Texas resident dropped in to share information on what Texas is doing.

Many states, including our own State of Ohio, now have Alzheimer bills enacted or under consideration. Ohio established a Governor's Task Force. Cleveland has one of the most dedicated

and creative chapters in the country, and Cleveland has a new Alzheimer's Center at University Hospital. Its director chairs the governor's Task Force on Alzheimer's Disease. Cleveland has established special day-care programs.

There's enormous energy and activity on the grass-roots level, the local community level, the state level and, of course, on the national level, and all of this is very good news. Yet, there is constant frustration, as well. These are difficult times, as you well know.

This Administration has created an enormous deficit, larger than the total of all national deficits since this nation was founded. This Administration has spent more money on military equipment research than has been spent in the last 50 years on biomedical research. It has spent more money on bombers, missiles and tanks than don't work than on the health of its people.

A few years ago Dorothy Kirsten, a world-renowned opera star, expressed her great frustration and anger about the lack of adequate resources for research that might have prevented her husband from falling victim to the disease. He was a brain surgeon. I share that anger; I know we all do.

At your last hearing, I testified that my husband was a very competent man, the administrative director of a major social agency in Cleveland, but Alzheimer's Disease is no respecter of competence.

I testified that when he was diagnosed, I had a responsible and challenging position at Cuyahoga Community College, but could not find a homemaker who could manage his strange, unpredictable and sometimes very angry behavior, so I had to resign my job.

I testified that the 36-hour day finally became more than I could manage, especially when all the familiar things were turning into terrible nightmares for him, when he was becoming highly agitated and paranoid and endangering himself, and it was frightening.

I testified that no insurance, public or private, covers the cost of what is defined as "custodial nursing home care," that is called "unskilled care," and yet I could not find people with the skill to deal with an Alzheimer victim. Nursing home care, at \$24,000 a year, was more than our combined pensions, and that was frightening, too. Then came the final devastating blow: after five months, the nursing home requested that I find another place for my husband—their personnel could not manage him.

Senator Metzenbaum, as you have heard today, there are common concerns running through the testimony of caregivers of Alzheimer's patients: the need for adequate home care, the enormous physical, emotional and financial burdens for the caregivers; the need for adequately trained people to help in the home or the nursing facility; the need for help with the financial problems, the nonexistent insurance, the high cost of nursing homes, the loss of jobs, the impoverishment of spouse or family; the desperate need for more research funding to unlock the answers for treatment, cure and prevention.

What I want our Cleveland friends to know is that those concerns are being addressed; that legislation just passed will provide some remedies; that competent, caring, dedicated people are working on the problems with them. And you have invited some of those special people here today so we can get a sense of the

progress in the past three years and a sense of what still needs to be done.

I believe I reflect your hope, as well as mine and that of so many others, that some of the exciting biomedical research, the drug therapy, the brain cell transplants, the genetic breakthroughs will provide answers soon. But until then, I know that we must and will continue to fight for more effective social support systems to help families cope with this devastating tragedy.

While all the problems have not yet been solved, the needs not yet met, progress is being made on the local, state and national level. Each one of us can make a difference and help push that progress forward. Each one of us can make a difference for future generations, for our children and grandchildren.

Senator METZENBAUM. Thank you very much, Evelyn. You spoke so well, I'm not going to fire you.

I will hold my questions, again, until the panel is completed.

Mr. Edward Truschke.

Mr. TRUSCHKE. My name is Edward Truschke, and I am President of ADRDA, the Alzheimer's Disease and Related Disorders Association.

Senator, Emerson once wrote that "He who has a thousand friends, has not a friend to spare," and I would like to begin by thanking you personally for the leadership role that you have taken in Congress on our behalf. And I know that I speak for all the families and health professionals connected with the fight against Alzheimer's Disease when I say that we consider you a true friend.

Although I know you are familiar with our association, perhaps it would be helpful to point out, for the record, that ADRDA is the only national organization representing the views and concerns of Alzheimer families. The association was first formed in 1980 by a handful of volunteers who were, and continue to be, committed to increasing public awareness and understanding, as well as to finding the cause and cure for this horrible disease.

The organization has grown rapidly since those early days when a Chicago businessman by the name of Jerome Stone pulled together a number of volunteers and started, with some \$70,000, an organization that has grown to the point where we now have more than 160 chapters and a thousand family support groups across the country. Throughout that growth, ADRDA has remained steadfastly committed to its original goals of research, education, patient care, advocacy, and family service.

Of course, an integral part of our effort has been to alert legislators and government decision-makers to those aspects of public policy which are deficient when it comes to this serious and growing problem. As evidence, I have submitted, for the record, ADRDA's National Program to Conquer Alzheimer's Disease. This document identifies some of the major public policy issues surrounding the disease, and offers recommendations for addressing these issues.

With your help and encouragement, Congress has begun to deal with some of the more pressing concerns of families, scientists and health professionals. For one thing, the support of you and your colleagues in Congress has gone a long way towards increasing the

Federal investment in medical research supported by the National Institutes of Health. Over the last seven years, in fact, that investment has grown from \$10 million to an estimated \$70 million this year. We hope next year's appropriations will take that investment even higher.

I hasten to point out, however, that more than money is at stake here. As a direct result of the Federal commitment to research, we have seen a ten-fold increase in the number of scientists dedicating themselves to research on Alzheimer's Disease. In fact, we're pleased to be here in Cleveland today to present Dr. Raj Klahara a major investigator-initiated award on behalf of ADRDA.

Before I leave the subject of research, I want to point out for the record that the specialized research centers, the Alzheimer's Disease Research Centers which you helped to launch three years ago, are contributing substantially to our knowledge base. As you know, these very centers will serve as sites for many of the THA clinical trials that were announced two weeks ago.

Medical research is and always will be a primary focus for our efforts. And to that end, since 1980, ADRDA has awarded research grants totalling \$6.5 million. Sad to say, Senator, we cannot depend on research alone. More to the point, and as you have heard today, we cannot ignore the 2.5 million victims of this disease, nor can we turn our backs on their families and loved ones.

Unless and until science comes up with a cure or effective treatment, society has a responsibility to help ease the burden now borne almost entirely by caregivers. By most accounts, families provide an estimated 70 percent of the care required by patients. Unless we offer them hope and help, we can expect to see more and more of these families succumb to the physical hardships and emotional stress that go hand in hand with providing constant care.

We also run the risk that these families will turn to nursing homes where, according to studies, it can cost society as much as \$50,000 a year to care for an Alzheimer victim, or more than twice the cost of maintaining the same individual at home. In short, Senator, providing a greater measure of care to families is not only good social policy; it is good economic policy, as well.

When it comes to health and social services, I suspect that few could disagree that Alzheimer families should be afforded greater access; the question is, access to what?

As the Office of Technology Assessment recently reported in its landmark study, "Losing a Million Minds—Confronting the Tragedy of Alzheimer Disease and Other Dementias," the fact is that our health care system is not well-suited to meet our needs. Services are difficult to locate, disorganized and fragmented, at best.

For this reason, we have joined with you in seeking Federal support for health services research; that is, research on ways to improve the organization, delivery and financing of health care to our families.

For its part, ADRDA has joined with the Robert Wood Johnson Foundation and the Administration on Aging in exploring opportunities for providing families with much needed respite care. At the same time, however, we recognize the need for a greater Federal investment in health services research. This is absolutely essential

if we hope to gain the knowledge required to construct responsive, high quality and cost-effective systems of care.

Finally, we are pleased to join you in support of S. 81, a bill you introduced earlier this year to, among other things, generate state activities designed to help ease the burden on families. If that legislation is enacted—and we certainly hope it is—it will lay the foundation for the kinds of support systems our families so desperately need.

Senator, we have come a long way together, but we still have some distance to go. I am convinced our journey will be shorter, so long as we sustain our research commitment, so long as we're not afraid to test appropriate avenues of treatment, and so long as we fulfill our responsibility to help families cope with this devastating illness.

Thank you.

Senator METZENBAUM. Mr. Truschke, I am happy to tell you that I attached S. 81, my Alzheimer's bill, in Committee—this subcommittee on Aging holding the hearing here today—to the Older American's Act. And I am pleased to report to you that that bill, the Older American's Act, has already passed in the United States Senate, and I'm optimistic that it will be passed in the House in the not-far-distant future. So we're moving with great dispatch, and I feel very good about that.

Our last witness of this panel is Dr. Brody. Dr. Brody, we're happy to have you with us, sir.

Dr. BRODY. Senator, thank you very much for inviting both myself and my wife, who helped prepare this testimony and, unfortunately, couldn't be here today.

Our names are Stanley J. Brody and Elaine M. Brody. I'm a professor of Physical Medicine and Rehabilitation in Psychiatry at the Medical School, Professor of Health Care Systems at the Wharton School, and Director of Research and Training Center for the Rehabilitation of Elderly Disabled Individuals at the University of Pennsylvania. I have also been privileged to be a member of the OTA Advisory Group on Alzheimer's.

Elaine Brody is Associate Director of Research of the Philadelphia Geriatric Center, Clinical Professor of Psychiatry at the Medical College of Pennsylvania, and Adjunct Professor of Social Work in Psychiatry at the Medical School of the University of Pennsylvania. I'm pleased to report that she is a member of your new Advisory Committee on Alzheimer's.

I hope that you will accept our written testimony as we prepared it for the record.

Senator METZENBAUM. Thank you very much. All of the written testimony that has been submitted will be included in the record, notwithstanding the fact that the witnesses abbreviated their remarks to sort of conform with our time constraints.

Dr. BRODY. Thank you, Senator.

Alzheimer's disease is a chronic and progressive impairment of the brain which results in disability that are behavioral in nature. These patient behavioral problems, as you heard, include anger, delusion, paranoia, wandering, sleep and wakefulness disturbances, inappropriateness—behaviors that are social in nature. In addition,

the patient experiences progressive deficits in activities of daily living, such as dressing, toileting, eating and bathing.

Now, all of the available research data—and there is more and more of it every day—deluges us with descriptive reports that lead to the inescapable conclusion that Alzheimer's Disease directly affects all members of the family and the family as a whole. We have heard that so eloquently today.

The concrete caregiving activities required and the emotional consequences have unique aspects that often push the strains of family members to an extraordinarily painful level. In short, when an older person becomes demented, it is a family event and the family is at risk of mental health problems.

The weight of accumulated evidence suggests that care of the demented patient is the most difficult form of family help, produces the most strain for caregivers, as we have heard; interferes the most with the caregivers' work life, and has more negative effects on family lifestyles.

It has been called the most socially disruptive of all ailments and is more damaging to family relationships and to the mental well-being of the caregiver than when the older person being cared for is just physically disabled, and this care is not a short-term proposition. The average length of time a family provides care—and we've heard that again this morning—is about five years, and many of them—as we have also heard—go on much longer.

A special form of family caregiving, that has been given little attention, occurs after the elderly family member has been placed in a nursing home. And, contrary to popular belief, the family does not cease its support of activities when the older person enters institutions, nor do family strains disappear, though they may derive from different kinds of factors. Family concerns, interest and contacts with the institutionalized older person continues.

The "what needs to be," in terms of caregiver support, is a question to be answered thoughtfully by society, and this is a question you have put to us today. For any given family, at what point is the goal to encourage continuing caregiving, no matter the psychological and social cost to the family and its members? At what point, do our values dictate that we help them to reduce the amount of care they provide.

The answer that our society has provided at this point is "very little help indeed" to reduce the amount of caregiving when needed. To a large extent, this is predicated on a societal bias against disability, particularly those of a behavioral nature, and a devotion to high tech, acute care-oriented medical solutions for disease problems. In another sense, it is because we lack the political will.

We all agree, and we have had testimony that I can date back to 1961—that integration of services is necessary. We can all agree that long-term care services that are social in nature, in the community and in institutions, are necessary and parallel the medical service we already provide. Where we disagree is on what can be done about it. That is the political will.

There's a generation gap in the political will issue. The budget deficit today is not caused by social services and by expansion of services to people.

Social planning has been successful. The Social Security Act has literally eliminated starvation in this country.

In 1935, before the passage of the Social Security Act, 75 percent of all old people were totally indigent and paupers. Half of them were dependent on their children for economic support. Today perhaps 1 percent are dependent on their children for economic support, and no more than 2½ percent are totally dependent on SSI for their sustenance.

In 1965 when Medicare was enacted, the same picture presented itself; at that point, families were paying and going into debt to take care of parents going into hospitals—a hospital stay cost \$360 in those days, and the average income for old people was \$1,000. There was an economic catastrophe for both family and the old person themselves when they had to go to the hospital, and we have solved that problem.

Today we are up against a new problem that of catastrophic long term care. Let me suggest that social planning has been successful in answering past problems of the elderly and can again.

We're into a generation gap. We're into a sense of what we can't do; a lack of political will and concept.

As long as there are different forms of funding, you're going to need band aids of studies, and coordinating mechanisms—we have many of them being proposed at this hearing—and information and referral mechanisms and the like.

The data is so clear—until we get a single form of funding, until we expand Medicare to include all of this kind of services that you've heard these folks say they need today, we're not going to make headway on the service part of this picture.

Senator METZENBAUM. When you use the phrase "generation gap," would you expand upon that for a minute, because I'm not quite sure I'm following what you're saying.

Dr. BRODY. What I'm saying is that the generation perhaps, that I represent, have experienced dealing with catastrophic issues successfully through political mechanisms. I'm talking specifically about the Social Security Act.

It's the lack of that experience on the part of this generation of legislators that basically leads them to say, "But we can't do it." One legislator participated in the enactment of the original Social Security Act. Perhaps, two dozen were serving during the passage of Medicare. Collectively, there is little legislative experience that would provide the basis for a positive approach.

The problem is that we aren't saying, "I know we can." That's what I'm talking about in terms of a generation gap in the experience that tells us, "Yes, we can resolve these problems." And we can use Government. There's nothing wrong with Government and governmental responses.

I've covered specific solutions on how we may approach this in my written testimony, and I'm not going to take your time today, except to re-emphasize that the time to act, in terms of "what needs to be" is right now. There are viable proposals before Congress that provide succor to the stressed and strained caregivers of Alzheimer's patients and other functionally disabled.

The Medicare Long-Term Home Care Catastrophic Act of 1987, introduced by Congressmen Pepper and Roybal, provides a basis for

immediate action. As you know, that is going to come up in Congress—certainly, in the House—in January.

As long as—I want to emphasize this again, as long as you have different funding streams for service, you will have to improvise with all kinds of—if I may use the word “gimmicky”—coordinating and costly integrative mechanisms.

It's time to responsibly answer the question of when do our values dictate that we give help to caregivers to reduce the amount of care they provide. The time is now to provide caregivers with the options, both in terms of community and institutional services, so that families can be preserved, and we give this help in the form of an extension of Medicare, a single funding system.

It is feasible. As I point out in my written testimony, it is not a bottomless pit. It requires political will.

Elaine Brody and I have been testifying before this Committee for almost 20 years, and we appreciate the opportunity to share in its valuable work, for not only older citizens but for all the generations of the aging family.

[The prepared statement of Drs. Stanley J. and Elaine M. Brody follows:]

Testimony on

CAREGIVER SUPPORT: WHAT IS, WHAT NEEDS BE

by

DRS. STANLEY J. BRODY AND ELAINE M. BRODY

Before the

**U.S. Senate Committee on Labor and Human Resources,
Sub-Committee on Aging**

August 19, 1987
Judson Park Auditorium
Cleveland, Ohio

Caregiver Support: What is, What Needs Be S.J. Brody

Our names are Stanley J. Brody and Elaine M. Brody. Stanley Brody is Professor of Physical Medicine and Rehabilitation in Psychiatry at the Medical School, Professor of Health Care Systems at the Wharton School and Director of the Research and Training Center for Rehabilitation of Elderly Disabled Individuals at the University of Pennsylvania.

Elaine Brody is Associate Director of Research at the Philadelphia Geriatric Center, Clinical Professor of Psychiatry at the Medical College of Pennsylvania, and Adjunct Professor of Social Work in Psychiatry at the Medical School of University of Pennsylvania.

Alzheimer's disease is a chronic and progressive impairment of the brain which results in disabilities that are behavioral in nature. These patient behavioral problems include anger, delusion, paranoia, wandering, sleep and wakefulness disturbances, inappropriateness—behaviors which are social in nature. In addition, the patient experiences progressive deficits in activities of daily living such as dressing, toileting, eating and bathing.

The medical support necessary to provide care for the patient for this chronic illness is primarily in diagnosis of the disease. Necessary medical treatment includes the provision of psychotropic drugs to help the patient modify behavior and skilled psychiatric counselling, particularly in the early stages of the disease, which may help patients deal with "excess disabilities," i.e., the patients' anxiety as they become aware of their behavioral problems.

The goal of rehabilitative treatment, is to maximize functioning, even with patients whose impairments have a downward trajectory. A key participant and tool of the rehabilitative process is the informal support system, or family.

All available research data together with a deluge of descriptive reports lead to the inescapable conclusion that Alzheimer's disease directly affects all members of the family and the family as a whole. The concrete caregiving activities required and the emotional consequences have unique aspects that often push the strains of family members to an extraordinarily painful level. In short, when an older person becomes demented, it is a family event and the family is at risk of mental health problems.

The main family caregivers are elderly spouses and adult daughters. Spouses and daughters provide nearly the same amount of help until the disabled older person becomes increasingly limited in activities of daily living (ADL) at which point daughters progressively provide more support. Since greater disability and dementia are associated with advanced old age and most people in advanced old age are widowed, it is likely that daughters are the ones who predominate in caring for the oldest and most demented elderly (most of whom are women).

Research has yielded a body of information that is so consistent that it is no longer at scientific issue and certain facts can be accepted as givens. Families of disabled older people have been dependable in providing care. As the "informal" system of care, they provide the vast majority of medically-related and supportive health and social services—assistance with activities of daily living (ADL) (e.g., bathing feeding, dressing, toileting) and instrumental activities of daily living (IADL) (e.g., laundry, household chores, managing money, transportation, shopping).

Caregiver Support: What is, What Needs Be S.J. Brody

Recent data from the 1982 Long Term Care Survey show that less than 15% of all "helper days of care" to people needing help with ADL are provided by the "formal" or non-family system. Moreover, only 4% of old people who need such help have any part of it paid for by government. The results of a Philadelphia Geriatric Center study of daughter-caregivers are similar: most nonfamily help was not subsidized but was purchased by the older people and their families.

Despite the difficulties of caregiving, services from the formal support system do not encourage families to shirk caregiving, but complement and supplement family services. In general, older people are placed in nursing homes only after strenuous and prolonged family efforts to maintain them in the community.

Families perform many other services that are not usually counted in surveys. They respond in emergencies, provide intermittent acute care, implement professional recommendations for rehabilitation procedures, and give the emotional support (concern, affection, socialization and sense of having someone on whom to rely) that is the most universal family service and the one most wanted by the old. The family also mobilizes, coordinates, and monitors family and formal services, a form of help that often is regarded as the province of professionals and characterized as "case management."

About half of all caregivers experience severe strains and mental health symptoms such as depression, nervousness, anxiety, sleeplessness, frustration, and lowered morale. These mental health problems are related to such factors as restrictions on time and freedom; interference with social and recreational activities, income, plans for vacations and for the future, privacy and use of space in the home. Many daughters feel "caught in the middle" of multiple competing demands on their time and energy such as responsibilities to their husbands, children, households, and jobs.

Alzheimer's Disease makes special and particularly arduous demands on caregivers. The afflicted people have disabilities that go beyond those of people with other diagnoses. Round-the-clock surveillance may be required because of disruptive, even dangerous, behaviors such as wandering, night-time wakefulness, turning on the stove or water faucets and leaving them untended. The patient may have sudden and upsetting emotional outbursts. The tasks of assisting with ADL are often more time consuming and problematic than for patients with other conditions because of the Alzheimer's patient's resistance and need for special management techniques. Embarrassing behaviors may discourage caregivers from having visitors in the home or taking the patient out. Particular distress is caused the caregiver when the patient no longer recognizes her and cannot provide her with feedback and appreciation for her efforts. Families often fear that the disease can be inherited.

Most of the symptoms found to predict caregiver strain are characteristic of many Alzheimer's patients--incontinence and the need for considerable help because of multiple deficits in ADL, for example. It is not the dementia per se that so often produces stress, however, but the disruptive behavioral manifestations of that ailment.

Sharing a household with a disabled older person is a strong predictor of strain. While mildly demented individuals may begin by remaining in their own homes, such arrangements cannot be sustained as the ailment progresses; virtually all noninstitutionalized Alzheimer's patients ultimately live with a caregiver. In a recent Philadelphia Geriatric Center respite care study, supported by the Hartford Foundation, of 634 caregivers of Alzheimer's patients, only 8% of the older people lived alone when first studied and many fewer did so a year later.

Caregiver Support: What Is, What Needs Be
S.J. Brody

A study by Linda George at Duke University found that, in comparison to the general population, caregivers to Alzheimer's patients experienced more stress, took more prescriptive, psychotropic drugs, participated in fewer social and recreational activities, and reported three times as many stress symptoms. Female caregivers (wives and daughters) were worse off than males on all of those effects.

Data from a Philadelphia Geriatric Center study of working and nonworking daughter caregivers also speak to the effects on the lives and well-being of those caring for a parent with Alzheimer's disease. Reports of depression among working women were related to having elderly mothers with dementia and worry about being able to meet those mothers' future needs. Furthermore, more than one-fourth of nonworking daughters had quit their jobs in order to take care of their disabled parents and a similar proportion of the working daughters were "conflicted" in that they had cut-back on their working hours and/or were considering quitting because of parent care. More of the mothers of both of these subgroups of women had dementia than did the mothers of the other daughters in the study and the daughters reported more problems and life-style disruptions.

In short, the weight of the accumulated evidence suggests that care of the demented patient is the most difficult form of family help, produces the most strain for caregivers, interferes the most with the caregivers' work lives and has more negative effects on family life styles. It has been called the most socially disruptive of all ailments and is more damaging to family relationships and to the mental well-being of the caregiver than when the older person being cared for is physically disabled, and this care is not a short-term proposition. The average length of time a family provides care is about five years and many go on much longer.

A special form of family caregiving that has been given little attention occurs after elderly family member has been placed in a nursing home. The role of the family in maintaining older people in the community is highlighted by the fact that, in contrast to those who live in the community, the vast majority of the institutionalized aged are not married (being widowed, divorced, or never married), more of them are childless, and those who have children have fewer children, older children, and children who are more geographically distant than the noninstitutionalized.

Though demented older people are overrepresented in nursing homes, constituting 50%-60% of the total nursing home population, an equal number live in the community. Whether in the community or in the nursing home they are the ones likely to need the most time-consuming care. Community care is often described as a less costly "alternative" than nursing home care, but it is not cheaper in dollars and does not avoid nursing home placement for severely impaired people such as Alzheimer's patients.

Contrary to popular belief, the family does not cease its supportive activities when the older person enters an institution, nor do family strains disappear, though they may derive from different factors.

Family concern, interest and contacts with the institutionalized older person continues. They talk to nursing home personnel about the older person, worry, feel guilty at having placed the patient (no matter how clearly the harsh realities had dictated that placement), are sad at seeing the older person's continuing decline, and experience depression and anxiety about their own aging. Families may be upset about the quality of care or staff attitudes, but are often in a bind—afraid to complain because they fear retaliation on the patient. When the patient has Alzheimer's disease, that fear is

Caregiver Support: What is, What Needs Be
S.J. Brody

intensified because the older person is relatively helpless, cannot communicate her needs to staff, and cannot report any negative treatment she may receive.

The "what needs to be" in terms of caregiver support is a question to be answered thoughtfully by society: for any given family, at what point is the goal to encourage continuing caregiving no matter the psychological and social cost to the family and its members? At what point do our values dictate that we help them to reduce the amount of care they provide?

The answer our society has provided at this point is very little help indeed to reduce the amount of caregiving when needed. To a large extent this is predicated on a societal bias against disability, particularly those of a behavioral nature, and a devotion to "high tech" acute care oriented medical solutions for disease problems.

Medicare, which was enacted 22 years ago was admittedly medically oriented to cure. The hospital with its array of machines and highly skilled technical personnel was the locus of treatment. Skilled nursing home care and home health care were restricted to short term, curative services. The administration of the program has been consistent with this societal perception.

At the time of the passage of Medicare, this was an appropriate response. Chronic illness was not seen as the critical problem that expensive acute care was. A hospital stay would absorb more than one-third of the average older persons yearly income and would impoverish supportive families as well as the older persons themselves. At least 20% of all aged and their families experienced at least one hospital admission a year.

At the same time, the Community Mental Health Act was legislated and seen by many policy makers as the proper response to acute and chronic mental health problems. Accordingly, payments to physicians for mental health care was limited by Medicare to \$250 a year with a co-payment of fifty percent.

The enactment of Medicaid was primarily to provide for indigent acute care patients and the provision of extended care, which was later translated to nursing home care, was not seen as a major program. With the increase of the number of disabled patients requiring nursing home care, the welfare aspect of Medicaid resulted in the pauperization of families before they could become eligible for a means oriented program.

Whatever social support programs there were, they were publicly provided within the context of welfare eligibility requirements. Ten years ago it was observed that the public response to the health needs of older people was one of acute care medicine rather than social support services which were more closely attuned to their situation. It was called a "thirty to one paradox" in that expenditures for acute medical care were thirty times those for support services. In the last ten years this has not changed.

The need for support of the care giving family of dementia patients is parallel to the needs of all chronically ill and their families. The recognition of the need for long term care in the home as well as in the institution was documented as far back as the 1961 White House Conference on Aging. This was confirmed by President Richard Nixon at the 1971 White House Conference when he observed that "the greatest need is to help more older Americans go on living in his or her own home."

Caregiver Support: What is, What Needs Be
S.J. Brody

Val Halamandaris of the National Association for Home Care points out that in 1974, the U.S. Senate Committee on Aging released a twelve volume report which followed 8 years of hearings and the accumulation of more than 3,000 pages of testimony. Thirteen years ago this comprehensive investigation concluded:

"Despite the heavy commitment to long-term care, a coherent policy on goals and methods has yet to be shaped. Thousands of seniors go without the care they need. Perhaps most unfortunate, institutionalization could have been prevented or postponed for thousands of current nursing home residents if viable home health care and supportive services existed."

In 1978 the House Select Committee on Aging unanimously passed a resolution calling for the expansion of Medicare's home care benefit. Ten years later we have not moved to provide public social supports to families who are caring for the disabled.

The activities of the Alzheimer's Disease and Related Disorders Association (ADRDA) have given new hope not only to families of Alzheimer patients but to all caring families. The recent ADRDA Inspired Office of Technology Assessment report to Congress "Losing a Million Minds" points out the similarity of the stress and strain of all care giving families, although noting the special strains caused by the behavioral problems of the Alzheimer patients.

Congress has now begun to move, almost imperceptibly, in the direction of expanding Medicare to provide long-term benefits for the chronically ill. In the recently passed Catastrophic Health Bill, H.R. 2470, by the House of Representatives, the Medicare Act is proposed to be amended in part by: (1) expanding Part B, physician services; to increase reimbursement for mental health services from \$250 to \$1000 a year continuing the 50% patient co-payment; (2) initiate a prescription drug reimbursement with a \$500 deductible and a 20% co-pay; (3) initiate reimbursement of 80 hours a year for respite care. Medicaid is amended to modify spousal impoverishment caused by nursing home placement, allowing the community dwelling spouse to retain \$925 a month and \$12,000 of liquid assets.

The significance of these changes is the recognition of the need for insurance against mental health costs, the acknowledgement of the high costs of prescription drugs, and the beginning of reorienting the Medicare Act, however slightly, by the inclusion of the social support service of respite care.

While the improvement of the financial lot of spouses who have worn themselves out caring for their disabled partners and who finally place them in a nursing home using the Medicaid program, is a humanitarian move and a partial recognition of the caring family, it avoids the real solution of providing, through Medicare, for nursing home care which would make spending down to Medicaid eligibility irrelevant.

These partial and often misleading responses to the "needs to be" of services for caring families are barriers to a meaningful solution. The "Lullaby bill," that is the Catastrophic Care Bill will lull aging families into believing they are covered for long-term care services. Indeed, 80% of all aged think that Medicare already covers them for such care. The President, in introducing the Bowen version of the Catastrophic Care Act asserted that this new coverage would give the elderly "that last full measure of security that fights the fear of catastrophic illness."

Caregiver Support: What is, What Needs Be
S.J. Brody

Social response lags because of the lack of awareness by aging families. Mass denial is the barrier to the perception of continuity of care as an economic catastrophe that could confront all aging families. The concept of "ageism" is in fact "age disabilityism". Just as society in general has traditionally rejected the disabled, that bias is continued into an aging society. The elderly themselves do not anticipate disability before death; disability is expectable but never expected. Since the event is not contemplated, the economic disaster that often accompanies it comes as a surprise.

Protection for long-term care needs would help families to do what they have been doing and want to do to help the elderly, and would prevent family breakdown that results from the excessive strains so many experience. The issue, in terms of public policy, is to protect the aging family as well as the aged disabled individual from catastrophic need. It is a publicly insurable risk.

Most private insurance programs offer no succor to the disabled elderly. The few policies offered are indemnity-oriented and usually limited to institutional care. Selling insurance coverage for nursing home stays to the aged who live in dread of that possibility has not been successful. In the few instances where modest indemnity coverage has been offered for community as well as institutional care, the marketing has also failed. Private insurance premiums anticipate as much as a 50% gross return and, accordingly, result in high premiums with minimum benefits. Seventy-nine percent of the potential aged consumers report that they think that Medicare covers them for long-term care, although it does not. Almost 70% of the elderly are covered by some form of Medigap policy; almost none of which cover continuity of care beyond the acute stage. The way the Medigap policies are offered by advocacy groups, as well as the media marketing methods by private insurers, and by this Administration, lulls elderly consumers into believing they are covered for long-term care.

Nevertheless, one of the first stages of policy development—that of defining the need for continuity of care—is well underway.

The disabled elderly have now been measured in terms of the number and nature of ADL deficits. While the level of the deficit provides a base line from which to measure change, the number of ADL deficits is emerging in study after study as the key to overall need for service as part of the continuity of care. Most old people in institutions have from five to six ADL deficits; 849,000 older persons living in the community also had five to six ADL deficiencies. They were the ones who used one-third of all informal and paid assistance and spent more than half of the total out-of-pocket expenditures. Furthermore, patients dependent in five to six ADLs were the ones most likely to exceed the average length of hospital stay for their DRG classifications.

Moreover there is increasing evidence that most of those suffering multiple ADL deficits are experiencing significant cognitive defects as well. Unpublished preliminary data from the current resident component of the 1985 Nursing Home Survey of the National Center for Health Statistics suggests that residents with a primary diagnosis of "senility" had an average of 4.8 ADL deficits. An earlier (1982) survey of community dwellers suggested that loss of cognitive functioning results in more functional limitations and that both of which "increase with age, increase dependency and the likelihood of nursing home placement."

If the need for catastrophic continuity of care is defined as having deficits in five to six ADL functions, then continuity of care is not a bottomless pit but one with clear dimensions. The number of the elderly in nursing homes has been steady for the last five

Caregiver Support: What is, What Needs Be
S.J. Brody

years at one million, partially as the result of more appropriate utilization. There is no compelling evidence that it will increase proportionately as the population continues to age. One-third of all skilled nursing facility (SNF) admissions are for less than 90 days, leaving about 600,000 as long-term residents who in the main are multiply dysfunctional. In sum, then, a total of 1.5 million elderly disabled or about 5% of the total population 65 years of age or over have more than five ADL deficits. This 5% may be objectively designated as at risk of economic catastrophe for the long-term care sector of continuity of care services. That figure is much lower than the 9% of Medicare beneficiaries who use, at a catastrophic rate, coverage for acute care. I suggest that, as each successive cohort of older people evidences an improved level of functioning, even in advanced old age, this is a manageable societal risk.

It is time then to act on "what needs to be." There already are viable proposals before Congress that provide succor to the stressed and strained caregivers of Alzheimer patients and other functionally disabled. The Medicare Long-Term Home Care Catastrophic Act of 1987 (H.R. 2762) introduced by Congressmen Pepper and Roybill provides a basis for immediate action.

It is time to responsibly answer the question of "when do our values dictate that we help caregivers to reduce the amount of care they provide". The time is now to provide caregivers with options, both in terms of community and institutional services, so that families can be preserved. It is feasible. It is not a bottomless pit. It requires political will.

Elaine Brody and I have been testifying before this Committee for almost twenty years and we are appreciative of the opportunity to share in its valuable work for not only older citizens but for all of the generations of the aging family.

Senator METZENBAUM. Thank you very much, Dr. Brody.

Mr. Truschke, if somebody has Alzheimer's now and they need a source of information, is there an 800 Hot Line that they can call to find out facts, answers to questions?

Mr. TRUSCHKE. Well, Senator, ADRDA has had, since its inception, a national 800 Hot Line that's directly connected to our office in Chicago, where we act as the gatekeeper, really, for all sorts of information that may come in from people concerned about whether a loved one has the disease or is demonstrating symptoms of the disease, to specific questions around medical breakthroughs and so on.

I mean our real focus and purpose there is that we put them in touch with one of our over 160 chapters around the country who can deal with their problems or answer their questions in a very direct way and, hopefully, refer them to other community resources or support groups that would help their situations. The answer to your question is yes.

Senator METZENBAUM. Are there additional studies that would be required in order to provide effective and cost-efficient in-home and community-based services? Dr. Brody, do you have an opinion on that?

Dr. BRODY. I have problems with your use of the word "cost effective." If we're going to provide additional services, it's going to cost money.

Senator METZENBAUM. I said "cost efficient."

Dr. BRODY. Cost efficient—it's different; I'm sorry.

Yes, there are studies on this. There is information on home care delivery. I think one of the big problems with home care delivery, as you know, if I may go back to my other point, is the multiple and different forms of financing.

Home care is restricted under the Medicare Act because it's a medically oriented bill, and so you virtually can't get any home care.

Our problem isn't so much in the study of efficient delivery of home health care but, rather, the provision of the home health care. As we get into it, we will continuously be faced with new kinds of problems of delivery of service, and we will meet them. Somewhere along the line we have to start.

Senator METZENBAUM. Somebody was just telling me yesterday about the shortage of nurses in this country and how difficult it is to obtain them. How about those who can provide adequate home health care in this area?

Dr. BRODY. You raise a very interesting point and a very important point. In Massachusetts they have run into exactly this problem. They have the funding for home health care but they can't get people to take the jobs. The reason for that, is that they're funding the jobs at such a low level, and they're treating them without much preparation or training.

We have to have a whole new reorientation about home health care, looking at it—as you heard from the testimony—teaching people how to deal with difficult older people or difficult Alzheimer patients, old or young, in terms of helping them with their activities of daily living. These are some of the problems that we're

going to face as we, hopefully, enact the legislation which will enable us to deliver these services.

Senator METZENBAUM. I want to thank this panel. I have other questions, which I will ask either by mail or talking with you directly. We have a third panel yet to be heard from, and I don't want to cut them short.

We will take a 5-minute recess at this time.

[Recess.]

Senator METZENBAUM. The hearing will come to order.

We have on our last panel Dr. Robert Cook-Deegan, Senior Analyst and Project Director of the Office of Technology Assessment, U.S. Congress; Zaven Khachaturian, PhD, Vice President of Research of the Medical and Health Care Division, University of Pittsburgh; and Peter Whitehouse, MD and PhD, Director of the Alzheimer's Center, University Hospital, Associate Professor in the Department of Neurology, Case Western Reserve University, Cleveland, Ohio.

Dr. Cook-Deegan, just because I named you first, we will hear from you first. I again would ask you to hold your remarks to five minutes, at the outside 10 minutes. And if you have a written statement, your entire statements will be included in the record. Thank you very much for being with us.

STATEMENTS OF ROBERT COOK-DEEGAN, MD, SENIOR ANALYST AND PROJECT DIRECTOR, OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS; ZAVEN KHACHATURIAN, PHD, VICE-PRESIDENT OF RESEARCH, MEDICAL AND HEALTH CARE DIVISION, UNIVERSITY OF PITTSBURGH; PETER WHITEHOUSE, MD, PHD, DIRECTOR, ALZHEIMER'S CENTER, UNIVERSITY HOSPITAL, ASSOCIATE PROFESSOR, DEPARTMENT OF NEUROLOGY, CASE WESTERN RESERVE UNIVERSITY, CLEVELAND, OH

Dr. COOK-DEEGAN. I will follow the tradition of Dr. Brody and I will dispense with the written statement that I was going to use. Instead, I will focus on a few points that Dr. Brody made, and then I will continue, picking the main points out of my written statement.

First, I should explain who I am. I am Robert Cook-Deegan. I was the Project Director for the OTA Project on Dementia that resulted in the publication "Losing a Million Minds." That was done at the request of seven Congressional committees, including the Labor and Human Resources Committee and your Subcommittee.

One thing to mention in passing is as you noted early-on in your remarks—that it was very easy to get support for legislation relating to Alzheimer's Disease. I don't know what Evelyn's reaction was to that, but it wasn't my recollection that the Omnibus Health Act was all that easy to get through. Anyway, it did, after all those roller-coaster efforts; I think it is an extremely important step, and I'll come back to that towards the end of my remarks.

I will start with the title of our report. It was called "Losing a Million Minds" and, like everything else in the OTA report, it was the creation of our full staff. In fact, we were trying to find a way to characterize the report. The report really is a 540-page state-

ment of the problem and only a glimmering of some of the possible solutions.

The reason for that, I think, is that there are only two possible solutions to prevent the losing of a million minds. One is to support research in hopes of discovering a technical fix that would eliminate the cause of the problem in the first place; that is, find the means of preventing Alzheimer's Disease and other dementias, or find an effective treatment so that people don't develop the symptoms.

The second prong of this two-pronged policy approach is to deliver services to patients, and I'll focus most of my remarks on that, but I'll be talking about the role of research in doing that.

The first panel today focused very much on stating what are the daily realities of what's called the system of long-term care—in fact, it's kind of a hard word to use, "system," in connection with long-term care, because it's really not a system in most places in the United States.

What became clear early-on in our writing of the OTA report was that the main problem in policy relating to Alzheimer's Disease and dementia is the problem of long-term care. And Dr. Brody, I think, in his remarks, noted that probably the most important solution is to come up with the funding mechanism to pay for services.

The argument is that if you come up with a mechanism to pay for these services, then people will figure out what needs to be delivered. So it puts the cart before the horse. That's the argument. I don't disagree with that. I think financing is a very high priority item, and I think it's probably the top on my own personal list of policy priorities.

The point I would add to that, however, is that having a funding stream is necessary, but it is not sufficient. I don't believe that we know how to take care of people who have Alzheimer's Disease or dementia, in the current system of care.

Senator METZENBAUM. What was that last sentence?

Dr. COOK-DEEGAN. I do not believe that we know how to take care of patients who have Alzheimer's Disease and dementia. I think if we created a pot of money and said, "Here. Let's deliver services," it would not be at all clear which services should be delivered, and how and where. Addressing that is a central role of health services research.

I do want to make the important point that it doesn't say that financing is not important. It says that the financing in fact, is probably going to drive the need for health services research. But if financing is in place, it becomes even more important to figure out how to deliver the services.

Senator METZENBAUM. And the services you're talking about are the care that you give to that patient.

Dr. COOK-DEEGAN. That's right. Let me be a little bit more specific about that. The services I'm talking about are the ones that you need to compensate for the loss of a person's mind. In the case of Alzheimer's Disease, that means long-term care, over a long period of time. And it may mean day care; it may mean home respite care; it may mean nursing home care. It may mean some form of care that we haven't figured out how to put together yet.

Senator METZENBAUM. What do you think the timetable will be as far as when we will have an answer as to what we really ought to be doing?

Dr. COOK-DEEGAN. It's an open-ended question, and I think that the data are beginning to flow in. But I think your bill, in tandem with the Medicare demonstration that also went through last year, I guess about 30 hours before the Omnibus Health Act went through; those two, I think, will be the pillars of Federal funding to support research to figure out what to do.

I think about two years after they start spending the money—come October 1st for both of those programs—about two years from then the papers are going to start flowing in at a rapidly accelerating rate. Those two bills together would, in fact, quintuple the amount of money that's being devoted to looking at how to care for people who have Alzheimer's disease and dementia. That, I think, is going to more than quintuple the amount of information that we generate, because I think we're going to reach some sort of critical mass.

That doesn't mean that you don't want to implement things in the meantime; it means that I don't think it's going to become crystal-clear exactly what you want to do, though, for the next four to five years, at least. You will never know exactly what to do. It's always a question of balancing the perfect and the good.

For example, in the last three to four years, there has been an explosion of special care units around the United States in nursing homes. The concept is not new; there have been many of these. In fact, Dr. Brody has been working, with one of those special care units for over a decade. But there weren't very many until about three or four years ago. Now, there are 150, 200, maybe even 250 to 300 of those special care units. Nobody really knows where they are or how many there are.

Each of those care units is operated on a slightly different philosophy, with a different physical facility, with a different philosophy of what medications you give; whether you use restraints or not; is the patient allowed to wander or not?—training mechanisms. All those things are different among special care units.

The whole concept of special care units has not really ever been tested to see if it makes a difference for the patients; does it improve their condition? The data are not there. There's anecdotal information that suggests things but there's no quantitative information upon which to build a national policy.

Senator METZENBAUM. Generally speaking, Doctor, taking all of those facilities that presently exist, on a scale of one to 100, what kind of rating would you give them across the board, knowing some are going to be much higher and some are going to be much lower?

Dr. COOK-DEEGAN. I think the best of the Alzheimer's care units would be—if you're talking about the typical nursing home, they would be very close to 100. In fact, compared to standard care for Alzheimer's patients as of five years ago, they would be 120 or 130, I think, right now.

Senator METZENBAUM. And overall, would you—the best, you say, would be 100; would you give them an 80 across the board, a 70, a 90?

Dr. COOK-DEEGAN. I think those places that have special care units tend to be the higher standard units because they employ more innovative people.

But I must say that we, in writing the OTA report, sent one of our contractors out to look at some of these special care units, and most of them were not terribly different from the standard of normal nursing home care, but they were also brand new.

Senator METZENBAUM. Is the procedure to use a lot of sedatives?

Dr. COOK-DEEGAN. No. In many of these places, that's one of the distinctive philosophies, to try to get people off of chemical restraints and physical restraints. But there are exceptions. There was one special care unit, for example, that was visited in Texas that was, in fact, the third floor of a converted motel. Our contractor went up to the third floor and didn't find a single person except for the patients. There was urine on the floor. I mean it was in terrible, terrible condition, and that was a so-called special care unit.

Senator METZENBAUM. How many such facilities do we have in Ohio, Evelyn, if you know?

Ms. BONDER. I don't know.

Senator METZENBAUM. We will check how many there are in Ohio, and I will pay some of them a visit, unannounced, just to check for myself.

Dr. COOK-DEEGAN. I think that's a wonderful idea.

Senator METZENBAUM. I think it's a valuable procedure.

[The prepared statement of Dr. Cook-Deegan follows:]

TESTIMONY OF ROBERT M. COOK-DEEGAN, M.D.
SENIOR ANALYST AND PROJECT DIRECTOR
OFFICE OF TECHNOLOGY ASSESSMENT, U. S. CONGRESS
BEFORE THE SUBCOMMITTEE ON AGING
COMMITTEE ON LABOR AND HUMAN RESOURCES
U. S. SENATE
CLEVELAND, OHIO

RECENT PROGRESS ON SERVICES FOR ALZHEIMER'S DISEASE AND OTHER DEMENTIAS

August 19, 1987

Mr. Chairman,

Thank you for the opportunity to testify before your committee today. My name is Robert Cook-Deegan. I am a physician working at the congressional Office of Technology Assessment (OTA). I directed the OTA project that resulted in the recent publication, Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias. Since I last testified before you in July 1986, a great deal has happened to change national policies for delivering services to those with Alzheimer's disease or some other disease causing dementia. I will review some significant recent events, and cast an eye to the future.

Before I do that, however, I should summarize the main findings of the OTA report. These are described in somewhat more detail in the article that Peter Whitehouse and I wrote for the current Issues in Science and Technology which I have submitted for the written record. It became obvious early in the OTA project that there are two principal ways that the federal government — or any government for that matter — can address the problems posed by dementing illness. First, one can support biomedical research, in hopes of discovering a "technical fix" (a way to prevent the diseases or to treat them much more effectively). Second, one can improve the system

of care. The bulk of the OTA study focused on this second course of action because it has been relatively neglected until recently, and because the federal programs in delivery of care are much more complicated and politically difficult. The main conclusion of this part of the report is that the principal deficiencies in the care system are in the arena of long-term care — the type routinely required by those with dementia for many years because their brains become incapable of supporting independent living. OTA found that the present system of long-term care, particularly for those with dementia, is disorganized, fragmented, and poorly adapted to the needs of prospective patients and their families. One of the main conclusions of the OTA report was our fundamental ignorance of even the most important facts needed to deal with the looming crisis of dementia care. Data are so few and so incomplete that OTA could make only vague and sketchy suggestions about ways to improve the system. A major roadblock to improvement is more information.

Since July 1986, Congress has acted decisively to identify the needs of those with dementia. In the last hours of the 99th Congress, first steps were taken to fill these gaps. The Omnibus Health Act (OHA) of 1986 contains the Alzheimer's and Related Dementias Services Research Act which you cosponsored with Senator Grassley. This, together with the Medicare demonstration bill described below, will likely prove the most important acts of the 99th Congress in setting policies for dementia in the future. OHA authorizes a multiagency program of research to find out how many people are affected and how best to deliver care. If fully funded and implemented, this new law should begin to answer the pressing questions about which services and settings are needed, and how to pay for them. Another important feature of the OHA is the national information center, which should begin to systematize the dissemination of information from national centers to local centers and vice versa. The National Institute on Aging has already begun to plan for the information center. The program of health services research authorized by OHA awaits appropriations that would permit work to begin in October 1987.

A second major step is the new dementia demonstration under Medicare authorized

by the Sixth Omnibus Budget Reconciliation Act. This mandates that services not normally covered by Medicare be delivered to those with Alzheimer's disease and other dementias through 5 to 10 centers throughout the nation. The intent of this act is to demonstrate whether such centers might work on a national scale in the future. The Health Care Financing Administration has begun planning these demonstrations, and they may be underway as soon as next Spring.

In the meantime, the Robert Wood Johnson Foundation has begun a program to fund non-nursing home services based in day care centers. This work is being co-funded by the Alzheimer's Disease and Related Disorders Association (ADRDA) and may also be funded by the federal Administration on Aging, pending 1988 appropriations from Congress. ADRDA has also begun its own smaller grant program for respite care services.

In carrying out the research, it was a constant source of frustration to OTA that we had so few facts upon which to base judgments. Perhaps the preparation of an overview of federal policy on dementia will be able to be much more specific in the future, as the data from these various studies come in and the options for fixing the care delivery system become clearer.

Growing awareness of the lack of appropriate services for dementia patients in most communities has led to public and private efforts to establish the necessary services. Attention has focused so far on particular health care and social services needed by these patients and their families. Less attention has been paid to methods of locating and arranging the necessary services or helping families to do so. Yet each of the State Task Forces that has studied the problem of dementia has identified lack of information about available services and the difficulty of arranging services as two of the biggest obstacles in caring for persons with dementia. Likewise, in response to an OTA survey, family caregivers said that assistance in locating people or organizations that provide care and help in applying for Medicaid, Social Security Disability, SSI, and other benefits were the second and third most essential services (following only the need for a paid companion to give caregivers a rest).

OTA has just begun an assessment of methods of locating and arranging health and long-term care services for persons with dementia at the community level — a study requested by you and several other Senators and Representatives. Katie Maslow is directing the new OTA project, which officially began on August 1. The plan for that study is included for the written record. OTA will describe problems in service delivery systems and identify methods of service delivery that are successful in some communities and may serve as models for other communities. In this regard, Katie has talked with the Cleveland chapter of ADRDA about its information and referral services, and is interested in learning more about information and referral and case management services provided by the Benjamin Rose Institute, the Alzheimer Center of the University Hospitals of Cleveland, and other local agencies. Those in Cleveland have taken the lead in other areas as well.

Epidemiological research indicates some differences in the prevalence of specific diseases that cause dementia in different ethnic and minority group populations. More important for family caregivers and health care and social service providers, though, are differences in attitudes, beliefs, and customs among these groups that affect patterns of informal caregiving and their differential use of medical, mental health, and social services.

In April 1987, Cleveland hosted a conference on "Alzheimer's Disease and Minority Populations," jointly sponsored by Health Matrix and the Visiting Nurse Association of Cleveland, in cooperation with the Cleveland chapter of ADRDA and the Alzheimer's Center of the University Hospitals of Cleveland. We believe the conference was one of the first on this topic, and we understand that as a result of the conference plans are underway for outreach efforts — particularly to black families caring for a person with dementia.

But action on all fronts cannot await the various studies, demonstrations, and grants programs. What can be done in the next year? I believe there are several options for action by Congress.

OTA Testimony: Robert Cook-Deegan, M.D.

The appropriations process. The most fundamental policy solution to the problem of dementia is biomedical research. Several executive agencies share the responsibility for conducting this research for the Federal Government, principal among them the National Institute on Aging (NIA), the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS), and the National Institute of Mental Health (NIMH). Each has important work to do, and their job has just begun. There have been several exciting discoveries about Alzheimer's disease, Parkinson's disease, Guamian dementia and other dementing illnesses in the last year. In my opinion, these are a direct result of increased commitment to such research over the last decade. Many more scientific advances can be anticipated, but the appropriations process in Congress is the key. In addition, the multiagency program of health services research is a top priority. Your bill from last year has passed, but it requires funding for the agencies and also for the interagency advisory council and citizens' advisory panel.

Oversight of demonstrations and research. The various research programs and demonstrations in long-term care are just being planned or getting underway. Congress has a role in ensuring that they are begun, and more importantly that they are conducted in a way that will allow the current efforts to suggest models for national replication.

Quality of care. The issue of quality care, particularly in nursing homes, is currently before the Congress. The Institute of Medicine (IOM) has written a highly useful roadmap for improving the system. The OTA report contains suggestions for adapting the IOM framework to those who have dementia, a particularly vulnerable population. Provisions for measuring care and assessing quality among demented patients could be incorporated into the new bills.

Senator METZENBAUM. Dr. Khachaturian, may we hear from you?

Dr. KHACHATURIAN. Mr. Chairman, I speak as a science administrator, as a program developer, as a scientist and as a person who is committed to solving the puzzle of Alzheimer's Disease.

At present, I serve as the Vice President for Research of the Medical and Health care Division of the University of Pittsburgh, an institution that is the home of one of the 10 Alzheimer's Disease Research Centers. Prior to my current position, I served as the Director of the Office of Alzheimer's Disease at the National Institute on Aging.

During my 10-year tenure at NIA, I had the responsibility for developing a national program of research on Alzheimer's Disease, including the Center's program, the patient's registry program and establishing the Office of Alzheimer's Disease Research. Therefore, I bring to this hearing the perspective of one who has observed the growth of Alzheimer's Disease in this country very closely, at first hand.

My written statement, which I respectfully request to be entered into the record, provides my personal view of the future needs in research on Alzheimer's Disease. My message today is a paradox because it is a positive statement full of optimism about this devastating human condition which creates a hopeless situation for millions of family members and care providers.

Very briefly, I want to make a few points. Although Alzheimer's Disease presents one of the most complex disorders of the brain, neuroscience today is making rapid progress in untangling the mystery of this disease. Ten short years ago, we were drowning in a sea of ignorance concerning this disorder; now we are on the verge of finding out what causes it, and attempts are underway to find a treatment.

Ten years ago, only a handful of scientists—

Senator METZENBAUM. Wait a minute. I just want to get that straight. You say we're on the verge of finding what causes Alzheimer's?

Dr. KHACHATURIAN. That's right.

Senator METZENBAUM. That's very encouraging.

Dr. KHACHATURIAN. Ten years ago, only a handful of scientists in the world knew about this disease, while millions suffered in hopeless silence. Now it is a rarity to find a person who has not heard of Alzheimer's Disease. Families with patients find solace in support groups such as Alzheimer's Disease and Related Disorders Association.

Ten years ago, the challenge was to attract the attention of the scientific community, the Government and the public to the devastating consequences of this disease; now it is difficult to attend a scientific meeting in neurological sciences where Alzheimer's Disease is not a prominent topic. The public is well informed, and the Government has begun to make substantial investments in research.

Finally, as a country, we need to feel proud about the remarkable progress we have made. The achievements in science have been truly miraculous. We have advanced from near darkness to the

point where the possibility of finding the cause and treatment is a realistic expectation.

ADRDA has to be particularly proud of what it has achieved. It has been instrumental in mobilizing public opinion, stimulating Government to take positive action and for providing the scientific community the needed resources to fight the battle of scientific ignorance.

Mr. Chairman, you should be given special recognition for the role you have played in the Congress of the United States as the champion of this disease. Yet, we cannot become complacent with these achievements. There is considerably more to be done. The future challenges for the scientific community are enormous.

The scientific community needs the patience and support of family members to sustain them in their efforts to fight this difficult battle. Advances in scientific knowledge typically occur at a low pace; breakthroughs in science occur in mysterious ways, and at unexpected times and places.

The only way to accelerate the process of discovery in science is to increase the number of scientists working on the problem of Alzheimer's Disease. It is the same as in a beehive: the more bees working on comb, the more honey one gets.

At present, the private foundations, such as ADRDA, and Federal agencies do not have the necessary resources to fund all of the good ideas submitted to them for support. The Center's program has proven to be remarkably successful; yet, to date, they have been unable to achieve their full potential because they have not had the necessary support.

Specific areas of science that need further research are identified in more detail in my written statement. However, two areas of special emphasis should be noted: A. the chemistry of abnormal proteins; and B. the study of nerve cell membrane structure and function, because further study in these areas hold the promise of uncovering the cause and finding the cure for this disease.

Mr. Chairman, thank you for allowing me opportunity to speak. I would be pleased to answer any questions.

[The prepared statement of Dr. Khachaturian follows:]

THE NEED FOR FURTHER RESEARCH ON ALZHEIMER'S DISEASE

Statement by
Zaven S. Khachaturian, Ph.D.
before the Subcommittee on Aging of the
Committee on Labor and Human Resources, U.S. Senate

August 19, 1987
Cleveland, Ohio

In 1977 the National Institute on Aging (NIA) convened a consensus development conference to evaluate the available information on treatable dementias in the elderly. The report of the NIA Task Force indicates that cognitive impairment in the elderly, if diagnosed properly, can frequently be cured or ameliorated.

The frequency and cause of reversible cognitive impairments in the elderly is not well studied. The best current estimate is that ten to twenty percent of persons 65 and older identified as having cognitive intellectual impairment may have reversible brain disorders. This misdiagnosis is an extremely costly error and a tragic waste when it leads to long-term institutionalization. The prospect of many older people mislabelled demented, who could have returned to a productive life with appropriate evaluation and treatment, poses a challenging problem. To solve this dilemma, we must develop better diagnostic tools for assessing cognitive impairment in the aged, and acquire more knowledge about the mechanisms of brain aging.

An important issue associated with Alzheimer disease is that of accurate diagnosis. There is, as yet, no single test that can definitely identify Alzheimer disease in a person suffering from confusion and forgetfulness. Several investigators working on finding the cause(s) of Alzheimer disease feel that we are close to finding a simple test that will diagnose this terrible disease during a person's life. It may seem a minor victory. In many ways, the diagnosis of Alzheimer disease still carries a death sentence.

To address the scientific problems associated with early and accurate diagnosis of Alzheimer disease (AD), the NIA organized a research planning workshop on diagnosis of this disease. The recommendations of the 37 participants was published as a conference report in the Archives of Neurology 1985, 42:1097-1105. This article represents a compendium of the recommendations of the NIA Conference concerning crucial research issues in the diagnosis of AD.

Zaven S. Khachaturian, Ph.D.

Normal Aging:

We are still uncertain whether AD is a specific, discrete, qualitative disorder such as an infectious process, endogenous or exogenous toxic disorder, or biochemical deficiency, or whether it is a quantitative disorder, in which an exaggeration and acceleration of the normal aging processes occur and dementia appears when neural reserves are exhausted and compensatory mechanisms fail. The process of normal aging is relatively poorly understood. There exist no consistent, established values for what constitutes "normal" cognitive impairment and memory loss with advancing years; nor are the neurologic changes, the neurochemical changes, the neurophysiological changes, or the gross and fine anatomical changes that accompany normal aging well enough understood to provide a firm base for determining "abnormal" changes. After the age of 80 years, the brain of a patient with AD may be difficult to distinguish from that of an age-matched normal patient without dementia; it is also true that the brains of some elderly patients have few or no senile (neuritic) plaques or neurofibrillary tangles. Even at earlier ages, the neurofibrillary tangles and senile plaques that characterize the brain with AD may also appear in normal brain, although in smaller quantities. How best to determine the definitive pathologic lesions of AD on the basis of counts of neurofibrillary tangles and plaques remains controversial among neuropathologists. Until we achieve a better understanding of the normal aging process the diagnosis of AD will continue to be difficult, sometimes inaccurate, and, at least currently, a combined clinico-pathologic process.

It is essential that we place a stronger research effort into the basic mechanisms of normal aging. Molecular biology, cellular pathology, and the analysis of brain cell assemblies, studies of cell death and repair, changes in extracellular space matrix and cerebral ventricular size, synaptogenesis and synaptic loss, changes in ion and membrane transport mechanisms, regional and total metabolic abnormalities, changes in brain electrical activity, neurotransmitter and peptide changes, immunologic alterations and the many broader changes in brain functions associated with perception, cognition, and emotion that accompany the process of growing old, all of these aspects require more investigation. Only by obtaining better data for the normal biological, neurologic, and psychological mechanisms can the abnormal be differentiated.

Zaven S. Khachaturian, Ph.D.

Diagnosis vs. Etiology:

Another general strategic issue, concerns the priority of diagnosis over etiology as a primary goal of research. A disease may be diagnosed without its causes, pathogenesis, or natural history being understood and, as has been commonly demonstrated in the history of medicine, therapy and relief from symptoms can be provided to patients without curing or eliminating the disease. Parkinson's disease is an excellent example of this. The cause of Parkinson's disease is unknown but supportive therapy based on restoring lowered levels of the neurotransmitter dopamine has proved to be extremely beneficial to many patients. Of course, "rational" therapy based on an understanding of etiology and pathogenesis would be the only likely way to halt the course of the disease or to prevent it. The only therapies proposed or attempted in AD thus far derive from observations of cell loss and neurotransmitter level reductions. These can, at best, provide only temporary restoration of some lowered cognitive capability and perhaps only delay the inexorable death of cells and destructive metabolic and reactive changes in the affected neurons. In Parkinson's disease the neuronal damage in the substantia nigra was no different in an autopsy study of untreated patients and those treated with levodopa.

Definition of Alzheimer Disease:

The major difficulty in diagnosing AD involves the definition of the disease itself and its varied and, at times, subtle manifestations. Alzheimer's disease remains a combined clinico-pathologic diagnosis. The relationship between neuropsychological, neuroradiological, and neuropathologic indexes of the disease is not well understood. The patient whose condition seems to be borderline on the basis of near-normal neuropsychological test scores might show full-blown alterations of brain atrophy on neuroradiological examinations performed by positron emission tomography (PET) or computed tomography (CT). Neuropathologic study may show little or no changes at postmortem examinations of the brain of a patient whose dementia had fulfilled all psychological behavioral requirements for the disease during life. But if therapy is to be truly effective, diagnosis must be based on firmer ground. An additional

Zaven S. Khachaturian, Ph.D.

problem is that of clinically distinguishing AD from such diseases as multi-infarct dementia, severe depression, nutritional deficiencies, or Pick's disease, which may mimic or coexist with AD. Improper or incomplete diagnosis can result in depriving patients of therapy that could ameliorate conditions other than AD. A continuing effort to define the disease precisely must remain the substrate of all research in the field.

Psychological Tests:

Practical screening for AD in the elderly population requires the discovery of some reliable neuropsychological marker. Psychological testing is far from exact and behavioral indicators that mark AD are complex and varied. The search for neuropsychological tests that reliably distinguish AD from other dementias or from normal aging is further complicated by the fact that some features of AD can be seen in patients suffering from other conditions. The normal data are not yet adequate to provide good baselines and controls are difficult to establish. The problems of establishing normative data pervades all areas of AD research, e.g., neuropathology, neuroradiology, and neurochemistry, but the problem is especially difficult in neuropsychology. The complex of cognitive and behavioral impairment of patients with AD is so varied, broad ranging, and subtle in the early stages of the disease that to distinguish them reliably seems almost impossible. Ideally, there should be a short, easily administered test (using computer display, scoring, and record keeping) that could be given to large numbers of people and that would not only spot early-stage victims but would discriminate AD from multi-infarct dementia, depression, and other conditions. This ideal single test could also be varied and given at regular intervals to gauge the severity of the disease as it progresses, thus providing an objective means of establishing the effect of various therapies.

However, a single short test cannot evaluate each cognitive area, so an alternative to this strategy may be necessary, at least until we gather more information on the natural history of the disease and its complex manifestations. This alternative strategy is to use a panel of tests, knowing that even the most successful of

Zaven S. Khachaturian, Ph.D.

the neuropsychological tests currently used are correct in selecting for AD (as confirmed by postmortem examination) in only a percentage of the cases (variously estimated to be from 40% to 70%). By taking a statistical (Bayesian) approach and using more than one psychological instrument to test subjects, a more accurate diagnosis would be more likely, although composite testing requires more time, effort, and skilled personnel.

Test Validation:

The validation of diagnostic tests remains a crucial problem in all areas of AD research but especially in the area of neuropsychology. To achieve the greatest diagnostic accuracy, the validity of these tests must be confirmed on the basis of a full range of behavioral, neurologic, chemical, physiological, and neuropathologic signs. These signs would have to correlate highly with test results. The underlying difficulty, of course, is that these other confirmatory measures may also vary in reliability in some circumstances. Therefore, there is a need for establishing the statistical-probabilistic accuracy of these signs from other kinds of studies by pooling data from large-scale standardized longitudinal studies using computerized data storage and analysis.

Other Behavioral Measure:

Neuropsychological testing involving abilities other than cognitive ones may also be useful and important. Culturally deprived subjects, illiterate subjects, or persons from different cultures might perform poorly on a cognitive test, not because of the difficulty and inappropriateness of the test procedures. Tests of first-order capabilities such as visual perception, reaction time, or motor ability might be closer to measuring substrate levels of central nervous system integrity or disability without the complication of trying to measure abstract conceptual-cognitive behavior.

At the other extreme would be efforts to measure the very subtle changes in behavior that are the first signs of aberration to be noticed by family members. These changes might simply be too

Zaven S. Khachaturian, Ph.D.

difficult to assess in any other way than through reports by family members, friends, fellow workers, etc. If such reports are taken carefully and the information is standardized, they may be an important source of information on early stages of the disease and premorbid behavior.

Familial-Genetic Studies:

Pedigree studies investigating the familial-genetic aspects of AD should be established through central family registries that would maintain records on well-characterized AD cases. Family registries would also provide the means to study more closely the natural history of AD disease and to explore the hypothesis that there may be different varieties. An early-onset AD (formally termed "presenile dementia"), occurring at approximately 40 to 50 years of age, might have a more obvious genetic component, while a later-onset type occurring at the ages of 60 years and above might have a less obvious component and be more dependent on environmental factors. Genetic characteristics of the disease need to be confirmed, and a broad cooperative program of centralized record keeping and pooling of familial records, from worldwide as well as American sources, would speed this process. The genetic studies of schizophrenia supported in part by the United States government and based in Scandinavia are a good example of international cooperative efforts. In these studies investigators evaluated twins, adoptions, and family data from Scandinavian countries where family records are maintained by the government for generations. Information from international sources would also provide a good base for epidemiological studies that might suggest possible environmental precipitators of AD-climate, nutrition, disease, toxic, and other factors. For more immediate goals, diagnosis might be guided by a better knowledge of the familial distribution of the disease. Establishing cell lines for genetic research would also require a scrupulous tracing of family pedigrees.

Isolated communities or groups, who may have a high degree of consanguinity, may be especially useful in studies of the familial incidence of AD. Familial studies will help predict individuals who are at risk for the disease. Current observations indicate that individuals with close family members who have, or

Zaven S. Khachaturian, Ph.D.

have had, the disease are three to four times more likely to develop it than individuals with no AD in their families. More studies are needed to establish a familial incidence; to be truly representative these studies must go beyond the clinics and nursing homes and reach into the community.

Epidemiological Studies:

Epidemiological studies of AD might be designed to establish collaborative ties with existing studies in other areas. For example, the studies aimed at establishing risk factors of other diseases could include statistics and questions concerning dementias. Other current studies aimed at collecting broad information on old people could also be used to collect specific data on cognitive status or impairments. Such studies could form collaborative links to screening an entire senior population, in a defined region, with an instrument that can select out possible cases of AD; these cases then could be followed more closely for detailed data collection and final autopsy confirmation whenever possible.

Alzheimer disease and other dementing disorders of older age are common conditions in the U.S. population and the population of other developed countries. The U.S. population affected by Alzheimer disease has been variously estimated at two to three million cases. The imprecision and variability of the estimates of the incidence and prevalence of Alzheimer disease and other dementing disorders of older age stem from differences in diagnostic criteria, data collection methods and the underlying age structures in the populations studied. The need for more definitive epidemiologic research is underscored by this imprecision and variability.

Clear, operationally defined and reproducible diagnostic criteria are required for cases very early in the course as well as those with more advanced disease. The Work Group on the Diagnosis of Alzheimer Disease of the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association established a set of criteria for the clinical diagnosis of Alzheimer disease. These criteria may not be optimal for use in screening large populations as they were intended for clinical use and were not operationalized. Screening instruments with known reliability, sensitivity and specificity against

Zaven S. Khachaturian, Ph.D.

the current state of the art diagnostic procedures for the dementias of older age are required. These instruments must be culturally, socio-economically, and educationally non-biased for use in cross-cultural and international studies. The screening instruments must not be affected by repeat administrations and must be easy to use in large-scale population studies.

The development, standardization and validation of diagnostic screening instruments against subsequent neuropathological diagnosis is also required. Diagnostic screening instruments must be distinguished from clinical screening instruments where all presumed cases are referred for more extensive diagnostic evaluations. In some population studies, it will not be possible to subject each presumed case of dementia to an extensive diagnostic workup, so that instruments for the prediction of the probable underlying cause or causes are needed.

The development of more refined, valid and reliable methods for reconstructing histories of demented subjects and for interviewing proxy informants is also needed.

Examples of specific substantive research questions of interest include:

Is Alzheimer disease a single entity reflecting a single etiology/exposure, clinical and neuropathological picture? Are the neuropathological findings the "final common pathway" reflecting multiple and diverse etiologies and varied clinical pictures?

What is the natural history of Alzheimer disease? Does it vary by age of onset? By any other inherited or acquired characteristics?

Does the sex ratio remain constant throughout the age span?

What is the impact of Alzheimer disease on life expectancy? How does it vary by age at onset?

What are the immediate, pathologically verified, causes of death in Alzheimer victims?

Are Alzheimer patients excessively vulnerable to or protected from any other diseases or conditions?

Zaven S. Khachaturian, Ph.D.

What are the precursors of Alzheimer disease and other dementing disorders of older age? As reviewed by Mortimer and Hutton, several risk factors for Alzheimer disease have been implicated in small studies or postulated in the research literature. Advancing age is the only clearly acknowledged risk factor. A genetic predisposition has been observed in some families. Other suggested risk factors include advanced parental age, selective vulnerability to exposure to aluminum, exposure to slow virus, immunologic defects, thyroid disease and head trauma. The condition appears to be more common in women than men and perhaps slightly more common in black women than white women. There appears to be an association between Down syndrome and Alzheimer disease suggesting a chromosomal defect. The impact of geographic, socio-economic, racial, ethnic or cultural characteristics on the risk of developing Alzheimer disease are unknown. Intense investigation of non-affected people 90 years of age and older may prove to be a particularly fruitful approach to research about risk factors for Alzheimer disease and other dementing disorders of older age.

Longitudinal Studies:

Another important area of research need concerns long-term studies based on standardized procedures and careful controls. Such studies would allow pooling and comparison of data from all disciplines involved in the study and treatment of AD. Longitudinal studies would fall into two broad categories; studies collecting detailed information on individuals already suffering from AD and studies involving general populations of elderly persons. These latter studies would provide information on premorbid events and conditions of those who might come down with the disease. This approach should include efforts to establish and link centers in a network for the care and study of patients with AD; to establish a central resource for data and a processing center accessible to all investigators in the network; and to establish standard guidelines

Zaven S. Khachaturian, Ph.D.

and procedures for psychological testing, neuropsychiatric protocols, neuroimaging, autopsy, brain tissue storage and handling, data storage and handling, computer programs, measurements, and nomenclature. This would help to ensure precise communication and eliminate "contamination" of the data.

Progress in understanding and diagnosing AD will most likely come about through amassing, evaluating, and comparing data and material from many sources. Again, all data collected, both retrospective and prospective, will be maximally useful only so long as they are carefully screened for accuracy of diagnosis, relevance, and reliability and are comparable across studies.

Studies to Assess Risk Factors:

Any disease is a combination of genetic and environmental factors. In AD there seems to be a genetic component, but external toxic or infectious processes probably also play a significant role. The role of environmental factors is another central research theme that needs to be emphasized. As may be the case with schizophrenia, a susceptibility to AD may be genetically transmitted but a particular (still-unknown) environmental factor (or factors) must be brought to bear for the disease to appear. The wide range of symptoms and pathologic lesions seen in AD suggest that it is a complex of related diseases in which more than one gene is involved and more than one environmental factor may be required to precipitate it. (The differences between early-onset and late-onset AD suggested by some investigators lends some credence to the theory that this may be a bimodal disease, with the early-onset type being primarily genetic.) A concerted interdisciplinary effort to investigate all likely environmental possibilities will be necessary, not only to establish firmly the natural history of the disease and its etiology but to identify risk factors and warn those persons who, through family case registries, have been found to be susceptible.

Differences of Alzheimer Disease from Others:

No clinical feature of AD is unique to the disease, so that distinguishing it from other, similar disorders is difficult. Developing methods of firmly distinguishing AD from other nervous

Zaven S. Khachaturian, Ph.D.

system diseases should be a high priority for diagnostic research. Although effective treatment for AD is not yet available, there are useful therapies for various diseases that produce the symptoms of dementia. The danger exists that appropriate therapy that might bring relief or even cure might be withheld from some patients if their conditions are misdiagnosed. For example, the aged patient with dementia produced by severe depression might be helped by antidepressant drug treatment. (It is not universally accepted that depression per se produces dementia.)

Other diseases that can be confused with AD include Pick's disease, multi-infarct dementia and other forms of cerebrovascular disease, Parkinson's disease, hydrocephalus, nutritional deficiencies, amyotrophic lateral and multiple sclerosis, and dementias resulting from tumors and brain injury. The simultaneous occurrence of many diseases with AD adds to the difficulty of diagnosis. Carefully sorting out the presence of overlapping diseases is important for effective diagnosis and treatment.

A View on the Etiology of Alzheimer Disease:

Speculations concerning the aging brain and systematic studies of age related changes in the nervous system have a long history. However, it is only during the last decade that neuroscientists have begun to investigate seriously a broad spectrum of topics in the neurobiology of aging. These range from basic molecular to clinical issues, and from the physical chemistry of membrane transport mechanisms to the neuropsychiatric assessment of the aging brain. Not long ago, little was known about "senility", and Alzheimer disease (AD) was considered a hopeless affliction of the aged. Now we know that chemical and physical changes in the brain can account for some of the memory deficits in AD and benign forgetfulness of the aged. The remarkable pace of scientific progress in this area of research increases the likelihood that some forms of dementia may be treatable by manipulations of brain chemistry.

A brief review of the history research on dementing disorders of the aged indicates that the clinical manifestations of dementia was known and described by the ancients — Assyrian, Greek and Roman. Anecdotal evidence indicates the existence of dementia-like conditions perhaps have been a part of human affliction since

Zaven S. Khachaturian, Ph.D.

the beginning of the modern man. However, it was only recently, in 1906, that Alzheimer described the first correlation between clinical characteristics of dementia and pathological lesions in the brain of patients.

In the period between 1906-1970's, the principal scientific concerns focused on description of gross anatomical changes in the brain and identification of histopathological lesions. However, by mid-1970's, the investment in basic neurobiology research during the preceding quarter century and the consequent expansion in scientific knowledge began to pay off. A neurochemical deficit in the cholinergic system was associated with AD. Very rapidly by the early 1980's, the evidence for cholinergic involvement was well established, but the wave of neurochemical research indicated that AD may not be a single neurotransmitter deficit; the involvement of other neurotransmitters and neuropeptides became evident.

In the same period of the early 1980's, the finding that there is a selective cell loss in the basal forebrain of AD patients further reinforced the cholinergic hypothesis, but it also shifted the focus of research to the much broader question of why there is a selective cell loss; why certain brain structures or loci are particularly vulnerable to cell death. The selective death of cholinergic neurons raised the possibility that the neurochemical deficits in AD might be an epiphenomenon, i.e., secondary to cell death or metabolic changes. The finding of selective cell vulnerability had a profound effect on the types of research questions being pursued. Research on the etiology of AD rapidly diversified. The principal focus of research shifted from neurochemistry to protein chemistry, and the question of what factors contribute to cell death.

At present, it is not known why certain types of neurons are at risk for cell death in AD and whether such cell death can be averted by pharmacological means. There are several working hypotheses concerning the possible mechanisms of cell death. Some of the possible reasons for selective cell death which have become major foci of research include the following:

Infectious Agent(s) - It has been proposed that a transmissible infective agent might be involved in the etiology of AD. However, to date, it has not been possible to generate any con-

Zaven S. Khachaturian, Ph.D.

vincing evidence for this hypothesis. Rather than searching for an elusive infective agent, perhaps a more useful area of further research would be the search for the mechanism(s) by which known infective agents alter cellular function and/or structure.

Toxins - Both endogenous and exogenous toxins have been associated with neuronal death. However, to date no specific toxin has been directly linked with specific cell death in AD. The co-localization of aluminum with PHF and other elements within tangle bearing neurons has stimulated considerable research. But it is not clear whether aluminum accumulation is the cause or the consequence of the cellular pathology. The emerging story about MPTP, vis-a-vis Parkinson disease, raises the possibility that a similar toxin might play a key role in the etiology of AD.

Abnormal Proteins - Presence of abnormal proteins are regarded to be the hallmark of AD. Considerable progress has been made in understanding the protein chemistry of tangles and plaques. The location of the gene responsible for one of the amyloid proteins has been located and the chemistry of PHF is better understood now than a few years ago. However, it is not clear whether plaques and tangles have any direct role to play in the etiology of AD. These direct lesions are not unique to AD. Therefore, there is the possibility that occurrence of these lesions might be coincidental to the disease process, or might be secondary to a more fundamental defect in membrane function. We do not know how these lesions affect cellular function. It is presumed that abnormal insoluble proteins interfere with cytoplasmic transport and thus leads to cell death, but the evidence is not clear. We need to find more precise pathological markers that influence cellular function.

Blood-Brain-Barrier Changes - This is a crucial area of research which has obvious implication for the viability of neural tissue but suffers from limitations of tools/techniques available to study the various complex transport systems. The radio-labeled chemicals currently used have half life which do not allow adequate assessment of the integrity of the system.

Protein Synthesis - A defect in the machinery to synthesis new protein or to degrade those that are no longer needed may have serious consequences for the viability of neurons. Preliminary evidence indicates that there is a reduction in mRNA concentration

Zaven S. Khachaturian, Ph.D.

in AD brain compared to normals. This is an important area of research that needs to be confirmed. With the availability of tissue from rapid autopsy -- within twenty minutes after death -- it should be possible to obtain more accurate data.

Metabolic Abnormality - There is evidence indicating that AD might involve abnormal metabolic activity in affected neural tissues: 1) glucose utilization is diminished; 2) PDHC is reduced; 3) Biopsy material shows abnormal oxidative metabolism; 4) PET images show patterns indicative of reduced glucose utilization; however, these might be due to reductions in cell number. There is a need for more accurate assessment of neural metabolic activity since it may account for both changes in neurotransmitter chemistry and cell death.

Cerebral Blood Flow and Circulation - Studies of the dynamic changes in the structure and function of the cerebral microvasculature needs more studies to identify functional changes in the microvasculature which may degrade or alter O_2 and glucose transport systems in subtle but persistent manner. Such changes may not produce an immediate effect but may produce a chronic, graded hypoglycemia or hypoxic condition over a long period.

Membrane Proteins - Mechanism by which the structure, function and assembly of membrane proteins change in aging and pathological condition is an important issue for the etiology of AD. Spectral NMR data indicates that membrane structure changes in aging and AD. There is need to produce three-dimensional crystals of membrane imbedded proteins to study the constituent sub-units. The issue of how membrane structural changes affect function, particularly the effect on transport mechanism across membranes, is an area that needs much attention.

At the present state of our knowledge, the issue of what role a particular etiologic factor such as a toxic agent plays in the pathogenesis of AD needs to be examined in the broader context of other ideas concerning the etiology of this disorder, e.g., genetics, infective agent, metabolic disorder, blood-brain-barrier changes, and neurochemical deficits. This broader view is necessary because of the strong possibility that AD may not be due to a single event or an insult, but brought about by a series of different

Zaven S. Khachaturian, Ph.D.

events over a long period. In discussing the cause(s) and effect relationship of this disorder, it might be useful to use the analogy of an AND gate (a digital logic element) to conceptualize the process I have in mind. As is well known, an AND gate can have two or more inputs and one output. In order to get an output, it is necessary that certain well-specified rules (a truth table) be followed. That is, a discrete event has to take place at each of the inputs of the AND gate for an output to occur. The timing of the events at the various gates can vary almost infinitely, but once an event takes place its effect must linger on. The basic rule is that an input has to be present at all inputs at the same time for an output to occur. Now, transposing this model to AD, the input gates could be such events as: a) genetic predisposition for a metabolism or functional disorder; b) aging; c) cerebral microvasculature pathology so that there is graded but prolonged reduction in glucose and O_2 ; d) changes in oxidative metabolism due to enzymatic deficiencies; e) exposure to toxins; f) other changes in brain chemistry; and g) reductions in cerebral blood flow. According to the AND gate model, these events do not have to occur at the same time but each could produce a lingering effect which eventually might lead to cell loss and clinical symptoms. Therefore, to understand the etiology of AD, it might be important to examine evidence showing a relationship between a particular variable, such as toxins and AD, in the context of other preceding critical physiological events during the lifetime of the patient which may have predisposed the vulnerability of the brain to the disease. The types of needed research discussed above are extremely important because they provide a crucial beginning for piecing together the AD puzzle. It is now possible to formulate testable hypotheses that can provide a common framework for interrelating a number of the discrete findings reported in the literature. For example, in study after study, we are seeing the importance of calcium levels within the cell in terms of cell-to-cell communication and even the viability of the cell itself. Many of the AD related changes in the brain point to the possibility that the underlying cellular pathology is associated with a disruption in the membrane. Such a disruption of the system could be a consequence of: changes in the transport mechanism of the blood-brain-barrier, pathologies associated with walls of the brain microvasculature, e.g., amyloid deposition, severe hypoxia, ischemia or hypoglycemia; exposure to a neurotoxin; pathogenic agents, or infectious agents; other insults; or aging. Further study should allow us to develop integrated theories of aging and better understand the biological mechanism of diseases such as AD.

Conclusion:

Specialists from a number of diverse fields are studying the various aspects of AD including its stages, effects, causes, and manifestations. Information is exchanged through informal and formal networks that exist within disciplines as well as through formal publications. The great danger is that findings in one discipline may be important to another but never communicated. Regular information exchange mechanisms need to be established. This might be accomplished through regular publications and through interdisciplinary meetings where findings and applications can be synthesized and communicated to the field as a whole.

Senator METZENBAUM. Your entire statement will be included in the record.

Dr. Khachaturian, elaborate a little bit more on the fact of being close to a breakthrough as to the cause, if you would, please.

Dr. KHACHATURIAN. As I indicated to you, Mr. Chairman, that's a hope and a promise. It's full of optimism. I'm looking at the trajectory of where we started a few short years ago and how far we have come. If one were to extrapolate that, that advance, one could be quite optimistic that in our lifetime—and I mean 5 to 10 years—that we will have major breakthroughs.

One recent example is, for instance, last October the discovery of the gene that's responsible for making one of the key abnormal proteins was a remarkable breakthrough. It was not expected. We're now at the point of really understanding what makes up the abnormalities of the cells' surface. Scientists have the tools; it's just a matter of plugging along at it in a consistent manner that we hope to find what's causing it. Once we find what's causing it, I think treatment should follow.

Senator METZENBAUM. Do we know whether or not it affects just a localized area of the brain, or are we not able to localize it?

Dr. KHACHATURIAN. I think Dr. Whitehouse is much better qualified to speak on that. I think there are specific sites in the brain that are at risk for this breakdown of the cells. But it's pervasive throughout the brain; there are a large number of areas that are affected.

Senator METZENBAUM. Do we have any idea whether or not it's genetic, hereditary, or whether it may, in some way, be related to the environment, external causes? Do we have any evidence of that kind at all?

Dr. KHACHATURIAN. Genetics play quite an important role. We know that at least in one form of it, it's quite important, the familial type. There are many studies underway—some of them international—trying to pursue that lead, the genetic causes. In fact, I believe Dr. Cook-Deegan was involved in one of the early studies of that form.

Genetics also play, I think, in all of them. It is not a single cause, but it is a sequence of events that occurs that leads to it. That is, one could be predisposed to the disease genetically, and then later on in life something else has to happen, and something else; it's the addition of those several events that leads to the disease.

Senator METZENBAUM. Is there more Alzheimer's in the United States than there is in Zambia or in China?

Dr. KHACHATURIAN. There are reports that in countries like China, in countries like Nigeria, in this country, American Indians, some Mexican-Americans, incidences are reported to be significantly lower. Those are only leads, initial leads. These leads have to be studied more carefully.

The reason for this is that in these cultures perhaps the disease is more accepted, therefore, it does not come to the attention of the health care providers. Therefore, one could be misled by believing that the incidence is lower in these cultures. I don't know of any solid evidence that any culture has a lower incidence of Alzheimer's than we do.

Senator METZENBAUM. Dr. Whitehouse, we will be very happy to hear from you, sir.

Dr. WHITEHOUSE. Thank you, Senator. Thank you for holding this hearing and inviting me to participate.

I am the Director of the Alzheimer Center at University Hospitals of Cleveland, and I have been fortunate to work with Bob and Stanley on the OTA, Zaven with his NIA Centers, and Ed at the National Alzheimer's Association. I am also fortunate to have chaired the Governor's Task Force here in Ohio and work with the local chapters of the Alzheimer's Association in supporting legislation, which is serving as a model to bring Ohio to national attention. I also have had the privilege to provide testimony for you before, for your Omnibus Bill and your work on the Older Americans Act, and I thank you for the opportunity again.

You asked me to address the issue of progress since the last hearings you held in 1984. Certainly, progress has occurred at a very rapid rate. It's difficult to measure that progress, Senator—there are many different measurements one could use.

One can look at the genetics, one can look at drug treatment, one can look at brain transplants, one can look at broader areas of neurobiology. One can look at the productivity of the current NIA centers. One can look at the number of grants proposed and funded. One can look at the 75 review papers—review papers, not new contributions—review papers alone, in the literature. One can look at the backlog in the journals, of papers that have been accepted but not published. I think it's clear that science has come alive, that Alzheimer's disease is clearly become a major focus for neuroscience and molecular biology over the last several years.

I think also, Senator, we've made progress in another area, and that is recognition of an area which we have not focused our attention on adequately, the health care delivery system. We have not studied adequately and been innovative enough in providing services for victims of this disease and their families.

So as I address my comments to what can be done in the future, I will spend time talking about that. However, obviously, the investment in biological and basic research has to be continued. We need more Alzheimer Centers.

We have an embarrassingly small amount of money that is targeted towards combating this disease and finding the cure. But we have to awake to the need to ease the burden that you have heard so eloquently described by others this morning.

Our current system is fragmented, poorly understood and oriented toward a medical model. It is based on a model that many of us feel needs to be modified—in which our health care industry is divided into two major segments: hospitals, and nursing homes. These groups don't understand each other.

What we need in the future is a better coordinated system which is more community-based and based on a model of care delivery that includes not only the medicine but psychosocial models, as well.

The last thought that I would leave with you, Senator, is that I think it's important for us all to recognize that Alzheimer's is a lead issue for this society and for our science. Alzheimer's by itself is an important enough problem, but Alzheimer's Disease is right

there at the focus of our revolution in molecular biology and neuroscience. What we learn about science in studying Alzheimer's disease will contribute to understanding of other disorders that affect the elderly and the rest of our citizens.

I also believe that Alzheimer's disease is a lead issue for our health care delivery system. If we look at how to better care for Alzheimer's victims, we will be taking a look at our entire system and that, of course, is a monumental job. And, ultimately, as has been told to you already, how we do that job will reflect the values of our society about what we value as a society.

Those of us that are watching and supporting your leadership efforts in this area will continue to look to you to provide the kinds of public policy changes and recommendations that reflect those values. Thank you.

[The prepared statement of Dr. Whitehouse follows:]

Peter J. Whitehouse, M.D., Ph.D.

TESTIMONY FOR SENATOR HOWARD METZENBAUM

AND THE SENATE SUBCOMMITTEE ON AGING

AUGUST 19, 1987

Senator Metzenbaum, fellow witnesses, members of the ADRDA:

I am pleased to have the opportunity to testify today on the progress we have made in combating Alzheimer's disease, and to discuss the further advances we must make to win the short-term battles as well as the final war in defeating this disorder.

My name is Dr. Peter Whitehouse. I am Director of the Alzheimer Center at University Hospitals of Cleveland and Director of the Division of Behavioral Neurology at Case Western Reserve University in Cleveland. I am a neurologist with a Ph.D. in neuropsychology and training in psychiatry and basic neuroscience, and have spent my professional life studying diseases that destroy cognitive functioning. I work closely with the National Alzheimer's Disease and Related Disorders Association (ADRDA): I am a member of their Professional Medical Advisory Board, the chairman of their Respite Care Subcommittee of the Nursing Home and Patient Care Committee, and a member of their Task Force for Health Care Delivery. I am also currently Chairman of the Ohio Governor's Task Force on Alzheimer's Disease and have served as an advisor to numerous state and federal

agencies, as well as private foundations. Most recently, I have been a member of the Office of Technology Assessment Panel, which has issued a final report to Congress concerning the problems of Alzheimer's Disease called "Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias", a report I commend to your attention.

What progress have we made since you, Senator Metzenbaum, held hearings on this same subject here in 1984?... Considerable progress, in my opinion. We now know much more about the genetics of Alzheimer's disease and the role of chromosome 21. Our understanding of the biological changes in the brains of victims of this disease has increased tremendously. We now know that there are several chemical messenger systems affected by this disorder. Our knowledge of these chemical systems is leading to the development of new treatments. We know more about the pattern of cognitive impairment in AD and are training patients and caregivers to deal better with their specific impairments. Perhaps most importantly, we have come to recognize that, although tremendous strides have been made toward finding an ultimate answer to the disease, we need to face squarely the care problems of those who have the disease now and who will get it in the future. Senator Metzenbaum and his staff have been at the forefront proposing legislation to fill the gaps these patients and their families fall through.

What then do we need to do in the future? Fortunately, we do not have to wonder what we need to do next. We hear the same

thing again and again. The OTA report, the ADRDA, clinicians, researchers, the caregivers we just heard, any party you choose -- all agree. Our health care delivery system, driven by federal funding, is too strongly oriented toward the medical model for both acute medical care and long term care. What is needed to serve better the needs of victims of this disorder are services that are community based. Evidence is accumulating that these kinds of services prove cost effective by delaying institutionalization of victims and allowing caregivers to remain productive members of society.

What are these services? The consensus is that we need case management to coordinate the variable aspects of the care of these patients and their families, and make the care system more approachable than it is now. We need respite, training, counseling, adult day care, and hospice services to aid the beleaguered families of these patients. The emotional, social, physical, and financial consequences to caregivers and society as a whole are overwhelming, yet barely addressed by our health care system. Moreover, the victims themselves need psychological and social, not medical, services, yet many of these services unwittingly discriminate against the cognitively impaired. They need personal care, homemaker, remodeling, and transportation services that enable them to maximize function outside of institutions as long as possible. Finally, they need a directory of long-term care services to make the transition as easy as possible for victim and caregiver alike.

Yet, when we develop these new services, they must enhance -- not replace -- the family's role in caring for these people. Legislation should provide support for families in their efforts to keep their loved ones at home, and not create another costly, bureaucratic system that undermines efforts of home care.

Is this an appropriate area of AD in which to invest precious resources? Should we instead be putting all our money into biological research to find the cure? Clearly, the amount of biological research that is being done in AD is still small in comparison to other major diseases such as cancer and vascular disease. Although breakthroughs are being made in AD research and should certainly be supported as our investment in the future, that future will most likely be long in coming. There will be many more victims of this disease to care for before effective medical treatment is available. Therefore, we must provide a continuum of health care services that helps victims and families deal with the devastating consequences of symptoms of dementia now. We must recognize that the entire family is the victim of this disease and is best seen as the unit for care intervention.

This need for new forms of health care delivery that address of the entire Alzheimer's family is already reflected in activity in private foundations such as the Robert Wood Johnson Foundation, in the OTA Panel's work, at HCFA, at NIH, and at the National ADRDA. It is clear that new delivery vehicles, with built-in evaluation mechanisms for quality assurance and cost

effectiveness, are necessary to better address health care needs of AD victims and their families.

If you live to age 80 in this country, you have a one in four chance of having Alzheimer's disease or a related disorder, and today's 65-year-olds can be expected, on average, to live to that age. The need for these services will therefore only increase as the number of victims grows from 2.5 million now to 4 million by the turn of the century, which is 13 short years away. AD and other dementia victims are currently estimated to represent an astounding 50% of all nursing home residents, making this disease a driving force in the long-term care industry. Clearly, the care of Alzheimer victims will soon be driving the health care of the elderly, which ultimately drives the entire U.S. health care system. If we are to appropriately allocate increasingly scarce resources to serve the needs of all, we must understand this understudied part of the system that is consuming vast sums for unknown benefit. What we learn about care of AD patients and how we better organize our efforts to care for them will clearly have major consequences for health care for all of us, whether or not we are affected by AD.

We are fortunate in Ohio and in Cleveland to have strong scientific and clinical research programs, excellent innovation in health care delivery, and active local chapters of the Alzheimer's Disease and Related Disorders Association. Our political leadership in this state has recognized the need in this area by allocating state funds to establish research and respite programs. We are also fortunate to have national political leaders like Senator Metzenbaum, who have led the fight against this disease.

Senator METZENBAUM. Thank you, Dr. Whitehouse.

I would like to commend Dr. Cook-Deegan and the Office of Technology Assessment for your publication "Losing a Million Minds," which is available to anybody who would want it, and I'm sure that Dr. Cook-Deegan can tell you how to obtain it.

I want to say to you, Dr. Whitehouse, that I'm very pleased that there is an Alzheimer's Center here. University Hospital is to be congratulated for establishing the Center, for bringing you here as its Director.

Having said that and knowing of your close relationship with Case Western Reserve, I think you ought to urge that there be some further implementation of some courses or some time spent for medical students in connection with the whole subject of Alzheimer's and the care of Alzheimer's patients.

As Dr. Khachaturian has said, we don't have the answers—or I guess Dr. Cook-Deegan said, that we don't have the answers to exactly what to do. But I think some awareness of the problems, some training, whether it be six hours or 60 hours, I think would be extremely valuable.

I might say also, please be good enough, Dr. Whitehouse, to give Dr. Foley my special regards. At the last hearing, he appeared here. His sense of humor and his knack for helping laymen understand medical concepts was particularly helpful.

Dr. Khachaturian, this is the second time you have testified at one of our hearings, and we're always particularly pleased to have you with us.

What I would like to ask you, Dr. Whitehouse, or Dr. Cook-Deegan, or Dr. Khachaturian—I guess any one of you—Dr. Cook-Deegan says we don't really know how to treat the Alzheimer patient. And yet, don't we have some parameters that we should be made aware of? Are there any publications that the Alzheimer patient—the Alzheimer caregiver might have as to problems to anticipate, to expect, and how to react and what to do with respect to those problems? Are there such publications available?

[Pause.]

Senator METZENBAUM. I'm overwhelmed by your silence.

Dr. WHITEHOUSE. We're waiting for each other to answer.

Clearly, there are, and the Alzheimer's Association has really taken the lead in providing these.

Dr. KHACHATURIAN. The ADRDA has a number of publications that makes available what knowledge is available. The National Institute on Aging has an Information Office that makes material available to the layman in simple language, and with your assistance with the Omnibus Health Bill, will be starting a clearing house which would facilitate along those lines.

I want to add one other comment, Mr. Chairman. Although we do not know how to treat the patients, we do know how to manage the patients. We do know how to, perhaps, alleviate some of the excess burden by bringing more humanity to the manner in which we provide care.

Often, the care is provided in a way that robs the patient and the family of their dignity. We do know how to prevent that. Perhaps if we do at least that simple thing, we could bring about tremendous help to the family members. So we're not totally helpless in

terms of the management of the patient. We might not be able to treat them or be able to send them home, but we can do something, certainly, to reduce the burden.

Senator METZENBAUM. Dr. Whitehouse, you were at the recent Zurich conference. Were there any new thoughts, concepts, innovative ideas that you would care to share with us?

Dr. WHITEHOUSE. It was that Zurich meeting, actually, Senator, that some of the earliest reports of the genetic work, that has already been alluded to, were mentioned by people from NINCDS and from the Boston group. Also, a focus of the Zurich meeting for a number of years has been on innovative therapies, and some of the work on THA was reported there, as well.

Senator METZENBAUM. Such matters as what?

Dr. WHITEHOUSE. The focus of that meeting for a number of years has been on therapies, so some of the work on THA and some of the new drugs was reported at that meeting. So, yes, that meeting was an effective vehicle for communicating information.

The number of meetings on Alzheimer's Disease has absolutely increased dramatically. That's another, I suppose, sign of our progress. Many of those are international in scope, because of the international dimensions of this problem.

Senator METZENBAUM. Has there been any evidence at any point where the impact of Alzheimer's on the individual has gone upward and then suddenly there was some recovery, or is it just a constant kind of incipient illness that gets worse and worse in every case?

Dr. WHITEHOUSE. One of the clear-cut findings that has come out of some of the NIA centers and some other studies is that the rate of progression is very variable in different individuals. There clearly are, Senator, people who have a downhill course and then plateau and don't appear to get worse. So there are, clearly, people who don't continue that usual devastating route or course that we usually think of.

I don't think anybody, in a pathologically confirmed case of Alzheimer's Disease, has reported in which the individual has gotten better. But these cases of so-called—"benign Alzheimer's Disease," are very important to study, to find out why those individuals suffer a less devastating disease than others.

Senator METZENBAUM. I don't think I got a satisfactory answer before, and I'm trying to get one. Does Alzheimer's affect a particular area of the brain?

Dr. WHITEHOUSE. No. Alzheimer's affects several different areas of the brain and, in fact, Senator, there are still other areas of the brain that are being explored, that we're finding abnormalities that weren't described by Alois Alzheimer back when he first described the case. But as we understand each of those different areas and their contributions, to the clinical symptoms we will be able to better develop drugs to improve that system and to then help the patient and family with that behavior.

Senator METZENBAUM. Dr. Cook-Deegan, do you know whether there are good research programs that are presently going unfunded, and are there good potential research centers that are waiting for funding?

Dr. COOK-DEEGAN. Yes. Let me do a two-part answer to that question. The first thing I would like to say is, to back-track just to make sure that what I said is—I overstated my case. When I say that we don't know what to do, I think I'm paid to look at what's out there and doesn't work, so that's what I focus on. I will say that in the last 5 to 10 years there has been an incredible improvement.

Bearing on your last question, are there cases where patients have gotten better; the place where that can happen quite frequently is when a proper diagnosis is made; people who are taken off of medications or with other medical problems are found. In fact, the person who, nonetheless, has Alzheimer's Disease, their mental status will rapidly improve. So that's an aspect of treatment that has been neglected for a long time. There is a lot of prospect for improving people who already have Alzheimer's disease just by taking care of their other medical and physical problems.

In answer to your second question—Zaven has a much better idea than I do, he administered the NIA centers for a long time—but yes, there are absolutely lots and lots of ideas that are not being funded. I don't know what the percentages are this year, but for the last several years, NIH has been funding only about a quarter to 40 percent, depending on the institute, of the grants that are approved for funding by the Peer Review System. So there are an awful lot of ideas out there waiting to happen.

There are lots of core groups forming. I mean Peter, for example, is not NIA-supported through the center program although he has got a center. So there are lots of other groups of experts around the country that could benefit from increased scientific funding.

Senator METZENBAUM. My last question is, do you anticipate any special difficulties with the THA trials? Anybody can answer.

Dr. WHITEHOUSE. We're one of the sites for that project, Senator. The THA studies is a monument to a lot of people's efforts. It has been a very complicated study to put together. It has not followed traditional formats, and it has had problems as a result of that.

I think that it's an exciting study. This is a potentially toxic medication, and some of the problems we're going to have with this study are undoubtedly due to the fact that some people will have side effects from the medication.

I think, organizationally, we have a good team. And I know people are out there waiting for the answers, and we're working as hard as we can.

Senator METZENBAUM. I want to thank you who are the medical experts, and all the others who have testified this morning.

Some may say, "Do these hearings help at all? Do they have any impact upon the legislative process?" When you hear information, you get new ideas, new concepts. I had some hearings this week, as I mentioned earlier on the AIDS babies issue.

That legislation that I passed through the Senate on that subject came about because at a hearing, having nothing at all to do with AIDS babies, a woman referred to the babies that are left in hospitals and abandoned by their parents. I, at that time, turned to one of my staffers and I said, "Follow up on that and give me a report within a week and let me see what the situation is." To think that there were babies abandoned in hospitals was just shocking to me.

and, as a consequence, we passed the AIDS Babies Bill through the Senate about 10 days, 2 weeks ago.

These hearings are extremely helpful to those who legislate, whether at the local or the national level. I want to say to all of you, I am very grateful to you for your time and your consideration, your concern and your participation.

[Additional material supplied for the record follows:]

OTA PROPOSAL

METHODS OF LOCATING AND ARRANGING HEALTH AND LONG-TERM CARESERVICES FOR PERSONS WITH DEMENTIA

BACKGROUND

About 1.5 million Americans suffer from severe dementia, and another 1 to 5 million have mild or moderate dementia. Due to the aging of the U.S. population, these numbers are expected to double by the year 2000. There are no known cures for most of the diseases that cause dementia. Although biomedical research may eventually lead to cures, the problem of those who are affected remains.

Dementia is characterized by loss of memory, judgment, and other cognitive abilities in an alert individual. As a result of these cognitive losses, persons with dementia generally require 24-hour supervision, assistance with activities of daily living, and a variety of other health care and social services. Because of the lengthy course of most diseases that cause dementia, patients require assistance for a prolonged period. Because many such diseases are progressive, each patient may need different kinds of care at different stages of the illness to correspond to changes in his or her level of functioning.

Families and friends provide care informally for most people with dementia. Some patients have no family or friends who are able and willing to provide care, however, and many patients require formal services in addition to the care that family and friends can give. Formal services are provided by health care and social service professionals and by public and private health care and social service agencies. The National Institute on Aging has estimated that the current cost of caring for persons with dementia, including the cost of diagnosis, medical care, lost wages for family caregivers, nursing home and other formal long-term care, and other direct and indirect costs, is about \$40 billion

annually.

Public awareness of and concern about the problem of dementia, particularly Alzheimer's disease, has increased dramatically in the past few years. Congress has responded by authorizing increased funding for biomedical research, and, in the last session of the 99th Congress, for research and demonstration projects on health care and social services for persons with dementia. Most attention has focused thus far on discrete components of the overall care an individual with dementia may need (e.g. diagnosis, assessment, behavioral management techniques, nursing home care, adult day care, and in-home respite care), the availability of each of these services, and how they are paid for.

Relatively little attention has been paid to the question of how families and others can locate and arrange needed services. Yet each of the State Task Forces that has studied the problem of dementia has identified lack of information about available services and the difficulty of arranging services as two of the biggest obstacles in caring for persons with dementia. According to the National Alzheimer's Disease and Related Disorders Association:

(A) recurring theme in the history of each family's problems is the difficulty experienced in finding both medical and social resources for the diagnosis, management, and, particularly, the care of the patient whose mind and body are failing (ADRDA, National Program To Conquer Alzheimer's Disease, 1987).

For families who live at a distance from the person with dementia, the problems of locating and arranging appropriate services are especially severe.

A recent OTA survey of family caregivers found that many families did not know whether home care, board and care, respite, adult day care, or nursing home services were available in their communities. Almost half reported that they had difficulty finding a doctor who could adequately care for the person with dementia. When asked

about the most important services, families identified the need for assistance in locating people or organizations that provide care and for help in applying for Medicaid, Social Security Disability, SSI, and other benefits, as the second and third most essential (following only the need for a paid companion to give caregivers a rest).

The need for methods of locating and arranging services arises in part from the complexity and fragmentation of long-term care services at the community level—a problem that complicates access to services for everyone who needs long-term care. About 80 Federal programs provide or pay for particular long-term care services, either directly or indirectly. Federal regulations define eligibility, coverage, and payment policies for services provided by each of these programs. In many cases additional State and local government regulations affect the availability, quality, and cost of Federally funded services. Some State and local governments provide long-term care services that are not Federally funded, and services are also provided by many private agencies, each with its own requirements for eligibility, coverage, and payment. At the community level, these services are generally not coordinated. Overlapping services and gaps in available services are common, and there is often no single source of information about what services are available.

Although these problems affect everyone who needs long-term care, there are several reasons to suspect that locating and arranging services for persons with dementia may be different from and more difficult than arranging services for other kinds of patients. First, the services needed for persons with dementia may be provided in any of 5 different systems with separate administrative structures and funding mechanisms originating at the Federal level:

- the medical or physical care system that includes hospital, physician, nursing home, and home health care, with primary public funding through Medicare and Medicaid;
- the aging services system that includes Area Agencies on Aging, senior centers, and other programs funded through the Older Americans Act;

- the social service system that includes local public welfare and public and private social service agencies and protective service agencies, with primary public funding through Federal and State public assistance programs, Medicaid, and the Social Services Block Grant;
- the mental health system that includes State mental hospitals, community mental health centers, and private mental health providers and agencies, with primary public funding through Medicaid and the Alcohol, Drug Abuse, and Mental Health Block Grant; and
- the public health system, that includes local public health and community health agencies, with funding from a variety of Federal, State, and local sources.

These systems are generally disconnected at the community level, and providers in one system are often unaware of services in the others.

Some characteristics of persons with dementia may also make it more difficult to arrange health care and social services for them than for persons with other physical and mental impairments. Persons with dementia are often unaware of their condition and needs, and may refuse needed services. They are usually also unable to evaluate different care options or to participate in important decisions, such as nursing home admission or sale of a home. Thus, family members or others must make these decisions, often without knowing what the individual would have wanted.

Staff in many hospitals, nursing homes, board and care facilities, adult day care centers, community mental health and public health centers, and home care agencies are not trained to care for persons with dementia. An increasing number of long-term care agencies and facilities are now offering "special" services for persons with dementia. There are no agreed upon standards for evaluating such services, however. Nor are there standards for evaluating the quality of care provided for dementia patients and their families by any health care or social service agency. Moreover, some agencies say they have special services when they do not.

Finally, for a variety of reasons, families of persons with dementia often hold back

from seeking formal services until the situation is desperate. As a result, the process of locating and arranging services often occurs in an atmosphere of crisis.

EXISTING METHODS FOR LOCATING AND ARRANGING SERVICES FOR PERSONS WITH DEMENTIA

The Federal government directly or indirectly funds several mechanisms for locating and arranging services for people with physical and mental impairments. These include information and referral services provided through local social service agencies and Area Agencies on Aging, and case management services provided through local departments of social or human services, Area Agencies on Aging, and public health and community mental health agencies. Case management services are also provided through Medicare and Medicaid demonstration and waiver programs and through Medicare-funded Social/Health Maintenance Organizations (S/HMOs) in some communities.

The cost of existing publicly supported case management and information and referral services is not known. Nor is it known how well they work for persons with dementia and their families or which local agencies are best suited to assist persons with dementia and their families in locating and arranging needed services.

In some communities, private groups—notably Alzheimer's Disease and Related Disorders Association (ADRDA) groups—are providing information and referral and assistance to families and others in locating services for persons with dementia. Little is known about how these private efforts are organized and funded, how well they work, or how they relate to publicly supported information and referral and case management systems.

Hospitals have traditionally played a major role in locating and arranging long-term care services. In some cases, persons with dementia are admitted to a hospital with an

acute medical condition, but when that condition is resolved, it is clear to the physician, hospital staff, the family, and others that the person cannot simply be discharged home. Sometimes this is because additional care requirements resulting from the acute illness exceed the capacity of a family member who was caring for the patient prior to the acute illness. At other times, hospitalization may simply trigger a realization by family members and others that the patient's functioning has deteriorated to such a low level and that his or her care needs are so great that formal services are needed.

Hospital discharge planning units are usually responsible for developing a plan of care for patients who need long-term institutional care or formal services at home. This process—which may involve assessment of the patient's physical, emotional, and cognitive status and social supports; consultation with the patient, the family, the doctor, nurses, and others; and location of appropriate services—can be time-consuming. In the past, patients sometimes remained in the hospital for prolonged periods while a discharge plan was developed. Now, however, the Medicare prospective payment system and other public and private programs that create incentives for shorter stays are reducing the time available for discharge planning in hospitals. The impact of these changes on discharge planning for persons with dementia is not known.

Geriatric assessment centers have been established in some hospitals to provide multidisciplinary assessment, short-term treatment, and assistance with long-term care planning for elderly patients. Although most geriatric assessment centers serve inpatients, some also provide services on an outpatient basis. Some hospitals that do not have an inpatient geriatric assessment center have a geriatric assessment team that provides similar services to patients throughout the hospital. Both in- and outpatient geriatric assessment centers and teams serve persons with dementia. More information is needed about the number of hospitals that have such centers or teams, the number of persons with dementia they serve, and the feasibility and cost effectiveness of this model.

of long-term care planning for dementia patients.

The Veterans Administration (VA) provides health care and social services for some veterans with dementia, but many veterans are not eligible for VA services, often because they do not have a service-connected disability. Moreover, most noninstitutional VA services (e.g. home care, adult day care, and respite care) are only provided near VA medical centers and are therefore not available to veterans who do not live near one of the 172 medical centers. Little is known about how veterans with dementia who are not eligible for VA services or who do not live near a VA medical center are referred to non-VA services in their communities. Anecdotal evidence suggests, however, that the VA and non-VA information and referral and case management systems are poorly integrated in many parts of the country.

CONGRESSIONAL INTEREST

Since the topic of this proposal spans many different Federal programs, it also crosses the jurisdictional lines of several Congressional committees. Committees with authorization, appropriation, or oversight responsibility for Medicare, Medicaid, the Older Americans Act, and other Federal programs that fund services for elderly and disabled people, and the VA have expressed interest in the proposed study.

Request letters have been received from Senator Charles E. Grassley, the Senate Committee on Labor and Human Resources, the House Committee on Energy and Commerce, and the House Select Committee on Aging. Letters of support for the assessment have been received from the Senate Special Committee on Aging, Senator Frank H. Murkowski, ranking minority member of the Senate Committee on Veterans' Affairs, and Congresswoman Olympia J. Snowe.

Most of the interest expressed so far has been based on concern about improving

access to appropriate services for persons with dementia. Committees are particularly concerned about access problems related to the specific Federal programs over which they have jurisdiction. Individual Congressmen are concerned about the complexity and fragmentation of long-term care services at the community level in their own States, and in some cases, the competing claims of the aging service system and the social service or public health system that each should be the primary case management agency.

OTA has been asked specifically whether information and referral and case management services provided by the aging network (i.e., Area Agencies on Aging) meet the needs of dementia patients who are under 60 or 65. OTA has also been asked whether existing preadmission screening programs for nursing home care provide information and referral or case management in some communities.

There is agreement that publicly supported mechanisms should back up and support the efforts of private groups but not supplant them. Thus, several requesters and potential requesters have stressed the need to assess the appropriate role of families, voluntary caregiver support groups, and public and private agencies in the service delivery system.

Committees and individual Congressmen are intent on making home and community-based services available to help families and others keep persons with dementia at home and postpone or avoid nursing home placement. In contrast to placing an individual in a nursing home, maintaining the individual at home with formal long-term care services may require ongoing efforts to locate, arrange, and monitor services. Thus, effective information and referral and case management systems are needed to support the goal of providing services to persons with dementia at home rather than in nursing homes.

Finally, information and referral and case management services may have an

impact on the overall cost of long-term care for persons with dementia. Since such persons often require care for a prolonged period, they are likely to exhaust their own resources and to need publicly-funded services. Effective information and referral and case management may result in some persons with dementia receiving lower cost services in the community and avoiding expensive institutional care, thus saving public funds. The cost of case management, if publicly funded, and the cost of additional home and community based services provided for patients as a result of case management may outweigh any potential savings, however.

ASSESSMENT ACTIVITIES

The assessment will describe, compare, and evaluate existing methods of locating and arranging health care and social services for persons with dementia and develop estimates of their relative efficacy and cost to Federal, State, and local government and to private individuals and agencies. It will identify methods that are particularly successful in some communities and may therefore serve as models for other communities. The emphasis will be on the ways in which Federal program regulations and funding mechanisms support or could support State and local efforts and the efforts of private groups to create an effective service delivery system at the community level. The final product will be a report that presents the findings of the study and Federal policy options for improving service delivery and coordinating available services.

Related Work at OTA

OTA has completed an assessment of Federal policies for biomedical research on dementia and care of persons with dementia, Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias. That report discussed the characteristics of persons with dementia, the health care and social services needed by

such persons, the settings in which services are provided, and methods of financing them. The proposed study will build on the findings of that report to address the major Federal policy issue it did not address--service delivery methods.

The OTA assessment Technology and Aging in America briefly outlined models of service delivery for elderly persons who need long-term care. The proposed study will build on those models as they apply to services for persons with dementia.

Related Work at Other Agencies:

CBO, CRS, and GAO are each conducting research on long-term care issues, including the cost and quality of long-term care services and methods for targeting services and controlling access. OTA is not aware of any sister agency research on service delivery systems or services for dementia patients in particular.

Several executive branch agencies are conducting research and demonstration projects on health care and social services for persons with dementia. As a result of legislation passed in the last session of the 99th Congress, the number of projects in this area will increase greatly in the next few years. The primary agencies involved are agencies of the Department of Health and Human Services (the National Institute on Aging, the National Institute of Mental Health, the Administration on Aging, the Office of Human Development Services, the Office of the Assistant Secretary for Planning and Evaluation, the Health Care Financing Administration, and the National Center for Health Services Research and Health Technology Assessment) and the VA. Some of these projects relate directly to the topic of this proposal. For example, the Administration on Aging has recently funded a project by the Anchorage, Alaska, Alzheimer's Disease Family Support Group to establish a telecommunication/information network for family caregivers in remote areas.

Service delivery systems for all kinds of patients who need long-term care have been a focus of research (funded primarily by the Department of Health and Human Services) for the past 10 to 15 years, but data from these studies have not been analyzed in terms of the mental status of the patient. Data from the Channelling Demonstration Program, a large Federally funded project that compared two models of case management, are now available. One task of this OTA assessment will be an evaluation of these data in terms of patients' mental status.

Assessment Plan

The assessment will be carried out over 15 months and will involve:

- selection of an advisory panel;
- collection of information about existing information and referral and case management systems;
- identification of problems in existing systems;
- analysis of the ways in which Federal program regulations and funding affect existing systems;
- development of models of effective information and referral and case management systems;
- development of policy options.

Selection of an Advisory Panel

An advisory panel of 15 to 20 individuals will be selected to include people with expertise or experience in the following areas as they relate to care of persons with dementia:

- Geriatric assessment
- Case management - Nursing

- Case management - Social Work
- Case management - Research/Channelling Demonstration Project
- Area Agencies on Aging - information and referral and case management services
- Community Mental Health Centers - information and referral and case management services
- Public Health nursing - information and referral and case management services
- Social Health Maintenance Organizations (SHMOs) - information and referral and case management services
- Hospital-based outpatient case management
- Alzheimer's Disease and Related Disorders Association (ADRDA) - National
- ADRDA - State level information and referral systems
- ADRDA - Community level information and referral and case management services
- Family Survival Project
- Community respite care services
- Family support services
- Hospital-based discharge planning
- State level long-term care system
- Minority issues in the delivery of health care and social services
- Legal issues in the delivery of health care and social services

Senator METZENBAUM. The hearing stands adjourned.
[Whereupon, at 1:05 p.m., the Subcommittee adjourned subject to
the call of the chair.]

○